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# **What is it like to survive near-death?**

*~ An Interpretative Phenomenological Study of the  
experience of surviving sudden cardiac arrest ~*

Submitted to the New School of Psychotherapy and Counselling and Middlesex University  
Psychology Department in partial fulfilment of the requirements for the Degree of Doctor of  
Existential Counselling Psychology and Psychotherapy

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*February 2016, London, United Kingdom*

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## ABSTRACT

This dissertation explores outlook and emotional well-being in cardiac arrest survivors at least 2 years after the event. Ten participants were interviewed, using semi-structured interviews focusing on emotional and psychological well-being, and the material was analysed using Interpretative Phenomenological Analysis (IPA). Three superordinate themes were identified. The first highlighted psychological dissonance in the wake of sudden cardiac arrest (SCA); the immediate impact of surviving and awakening to hear that they had suffered SCA was sudden, unexpected and confusing. The second was existential loss, relating to what SCA represented during this transitional and assimilative period. Finally, the third was 'living in the here and now,' which characterized their post-transformative journey and view of life as meaning emerged.

Existing literature on the psychological and psychosocial effects of SCA on survivors was examined to shed light on the results. Existential themes of death, loss, and finitude, as well as an ontological awakening of conscious, meaningful and appreciative living, also proved useful. The clinical significance of the study included a recommendation to build awareness of the difficulty of emotional adjustment and increased availability of counselling and mental health support. The study also recommends a focus on peer support and ensuring that counsellors are familiar with or have experience of how this phenomenon affects many areas of life. The choice of IPA as a method is deemed a useful one, as its clear guidelines together with a solid methodological grounding informed both the quality of the interviews and depth of analysis. Further qualitative research is suggested on this prevailing area, using varied methodologies.

*Keywords:* Sudden Cardiac Arrest (SCA), Outlook and Emotional Well-being, Interpretive Phenomenological Analysis (IPA), Experience of surviving near (clinical) death.

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# 1 INTRODUCTION

When an individual goes into a state of sudden cardiac arrest, the heart has stopped, causing their body and brain to be without oxygen. As the heart, lungs and brain cease functioning (Parnia & Lunea, 2013), the beginnings of the biological process of death occur. Sudden cardiac arrest (SCA) is a medical term, meaning clinical death. Individuals lose consciousness quickly and will die if not treated within an hour. Timely resuscitation and defibrillation are both needed, in which an electric current shocks the heart so that a normal rhythm can resume. This can be in the form of an automated external defibrillator (AED) or implantable cardioverter defibrillator (ICD). This treatment attempts to reverse the effects of SCA.

The aim of this study is to explore and understand how adults experience life after surviving sudden cardiac arrest. This is the closest one can come to death and yet still survive. This study is concerned with the outlook and emotional well-being of survivors who had no awareness of pre-morbidity. The emotional experience of survivors has not been widely captured in research. This phenomenological inquiry will examine the nature of the experience of SCA and being close to death.

## **Personal background**

I grew up predominantly in Australia in the 1970s, in a small close family unit with traditional Italian values and culture. My father suffered a cardiac arrest as a result of an incorrect intubation in the hospital prior to a minor kidney operation. He survived, but remained in a semi-vegetative state before dying 2.5 years later. Being a toddler at the time, I do not have a living memory of this, although growing up there was always a sense of deep loss and tragedy in my family. I remain naturally drawn to seeking an understanding of life and existence through the lens of loss, death, and meaning. This includes how life is lived after a sudden close brush with death.

Professionally, I started my clinical placement training in 2010 by working with adults in a bereavement service. For three years, I counselled individuals who had suffered untimely and often tragic losses of loved ones. The existential themes around loss and isolation, meaning-making and values, and needing to gain a different perspective on their lives were quite often evident. I found myself wondering what existential themes may emerge for survivors of SCA. This

study hopes to fill a gap in SCA research, particularly in qualitative work. I have chosen to research this topic as this important phenomenon affects a growing number of people and can present without any prior illness or symptoms.

In the UK, there are an estimated 60,000 SCAs per year outside the hospital context, and survival rates are poor, varying from 2% to 12% (Malhotra & Rakhit, 2013). Emergency medical services attempt to resuscitate just over 30,000 people after non-fatal cardiac arrests, although less than one in ten survives to discharge according to the British Heart Foundation<sup>1</sup> and National Health Service.<sup>2</sup> However, with advanced medical interventions and community access to defibrillators, the number of people surviving SCA is increasing (Wilson, Staniforth, Till, das Nair & Vesey, 2014). As survival rates in the UK and elsewhere in the world have been increasing over the past 10 years, this decrease in mortality has led to an increased focus on morbidity in survivors of SCA (O'Reilly, Grubb & O'Carroll, 2003). Those affected have often intertwined issues around physical and cognitive impairment, social and psychological maladjustment.

My belief is that many people will view life differently after SCA, and I assume that outlook and emotional well-being are renegotiated. I aim to be constantly aware of this bias when conducting interviews as well as when analysing participant data in order to separate researcher subjectivity from the findings. In interviews, exploring lived experience through rich descriptions and detailed open narratives will provide space for the individual to tell their personal story. My attitude is one of moving dialectically from an awareness of my own preconceptions to being open to participant experiences (Finlay, 2009). When approaching participant data in this way, I endeavour to reflect on interpretations made regarding my own assumptive experience and that of the participant. This is in keeping with hermeneutic phenomenology in which bracketing subjectivity is not attempted, as a person is not seen as a 'blank slate' or neutral contributor, but rather holds their preconceptions at the forefront for further reflection. This study of survivors' lived experience will, I hope, provide further understanding and awareness of this phenomenon to a wider group of counselling and psychology health professionals.

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<sup>1</sup> [https://www.bhf.org.uk/~media/files/publications/policy-documents/final\\_nation\\_of\\_lifesavers\\_policy\\_statement\\_14102014.pdf](https://www.bhf.org.uk/~media/files/publications/policy-documents/final_nation_of_lifesavers_policy_statement_14102014.pdf)

<sup>2</sup> <http://www.england.nhs.uk/statistics/statistical-work-areas/ambulance-quality-indicators/>



## **2 LITERATURE REVIEW**

I have chosen literature of relevance to my study, including work on the emotional or psychological aspects of the well-being of survivors of SCA. The majority of quantitative studies have attempted to capture well-being under the umbrella term ‘quality of life’. This is determined by measuring the biological, psychological and social functioning of an individual. A few studies have focused on psychological symptomologies only, measuring increases in anxiety, depression and post-traumatic stress. These studies have all used a number of validated psychometric assessments in individual self-reporting. I have therefore put the quantitative studies into the following categories to capture survivors’ experience: ‘quantitative research on quality of life’, ‘treatment with implantable cardioverter defibrillator (ICD)’ and ‘quantitative research on anxiety, depression and post-traumatic stress disorder in SCA survivors.’

I have also found a small amount of relevant qualitative research, which refers to meaning-making using phenomenological methodology. This has been categorised as ‘qualitative research on making meaning out of the experience of SCA’.

As this study is concerned with outlook and emotional well-being, I would like to begin by clarifying these concepts in terms of their relevance to SCA survivors. I will then discuss different theoretical perspectives and ideas on emotion and well-being, in the context of this population group. This will show how each contributes to further knowledge, informing clinical practice. These include the cognitive behavioural approach, positive psychology, humanistic and existential orientations. For wider discourse, I will also be mentioning medical sociology.

### **2.1 Outlook and emotional well-being**

‘Outlook’ is defined as ‘a person’s point of view or general attitude to life’ ([www.oxforddictionaries.com](http://www.oxforddictionaries.com)). Individual thought-processes are inter-subjective, meaning they influence, and are influenced by, an interactive world (Merleau-Ponty, 1962). These include what one believes in, values, what one makes meaning of and considers to be of importance, including feelings. Van Deurzen (2005) states that ‘as human beings, we continuously transform our outlook on the world and in the process, we remodel our world’ (p. 265). This has particular relevance to SCA survivors, whose outlook may change after experiencing a sudden threat to life. This shift in

their life trajectory may mean their view on life needs renegotiating. Importantly, a focus on how survivors have made sense of their lives and what is now valued and important could help them regain a sense of autonomy and purpose.

‘Well-being’ is ‘the state of being comfortable, healthy, or happy’ ([www.oxforddictionaries.com](http://www.oxforddictionaries.com)). Focusing on happiness as a core component of well-being has been widely studied in the general population. In SCA studies, it is more commonly referred to as ‘subjective well-being’, meaning how people evaluate the quality of their lives (Diener, Lucas & Oishi, 2002; Keyes, 2006). Questionnaires ask how satisfied individuals are with life and their emotional reactions. However, rating ‘feelings’ (within the emotional reactions section) does not refer to a specific experience (Simsek, 2009). In survivors, it is difficult to assess intentionality where there is no reference to how one feels in the context of SCA and their lives afterwards. Nevertheless, how survivors report their state of well-being is important in how comfortable they feel at having assimilated their experience, weighing up the substance of their lives (Keyes, 2006). This may include elements of social integration, purpose in life and coming to a place of peace and contentment that contains both tension and balance (Healey-Ogden & Austin, 2011).

Exploring well-being from an emotional standpoint is particularly relevant to SCA survivors, who have often experienced disruption to their physical lives. The emotional aftermath of such a difficult experience has the potential to threaten well-being and it is therefore crucial to make sense of, or reassess their emotions in the context of, their changed lives.

## **Cognitive behavioural view**

The cognitive school of thought and its therapies remains dominant in psychological and healthcare fields, particularly due to its evidence-based and structured assessment of cognitions, emotions and behaviour. These assessments are often part of a wide number of psychometric tests used in quantitative research in SCA studies assessing emotional or psychological well-being, with a focus on how individuals appraise their situation, accessed through their thoughts, images, and memories as the target for therapeutic change (Bennett-Levy et al., 2004). How a survivor of SCA has structured their cognitive experience, including their attitude and assumptions (i.e. their outlook) will, in turn, influence their emotional state (well-being), feelings and behaviour.

The cognitive behavioural model (Beck, 1995) characterises negative feelings as the product of irrational and unconscious beliefs. These beliefs are thought to stem from childhood and can often be rigid and overgeneralized (Bennett-Levy et al., 2004) and gain significance for an individual, as it is through this lens that one views oneself, other people and the world. Arguably, thinking in a ruminative or inflexible way produces negative feelings and therefore it is necessary to reduce negative emotions by altering thoughts and beliefs (Bennett-Levy et al., 2004). Given a certain situation, an individual's response may trigger automatic thoughts affecting emotions, behaviour and physiological response. SCA survivors, having surpassed a sudden threat to life, need to make sense of this experience, and their future life will undoubtedly be different. This may challenge an earlier disposition or fixed mindset in survivors, who then need to re-interpret and make sense of their experience and outlook.

This model, therefore, suggests it is not the event itself producing negative feelings, but rather how one interprets and constructs meaning from it (Beck, 1995). One type of emotional regulation is changing how one appraises their situation through thoughts, images and memories in order to modify the emotional significance. It is suggested that, when reappraisal takes place, individuals experience less depression, have better social connections and more purpose in life (Hopp, Troy & Mauss, 2011). Changing how one feels about oneself arguably allows potential choices or goals to be uncovered (Garrett, 2010). For my population group, this has particular relevance where an individual's previous history, temperament, social and cultural background are all entwined with their outlook on life. It may be with the re-examination of their lives after SCA that earlier thinking patterns become more visible, creating more awareness of their state of well-being.

In a general sense, emotional regulation is important for psychological health and well-being, decreasing emotions deemed unhelpful, disempowering and unhealthy in favour of those that increase a sense of happiness, hope and wellness. However, for SCA survivors, this suggests that understanding emotions and their meanings are not at the forefront of treatment if one focuses on reversing uncomfortable feelings by disproving the validity of particular thoughts and beliefs. As a sole mode of treatment, assuming a barometer of normality implies that certain thoughts are not permitted, and therefore an individual cannot make sense of the relevant event and feelings (House & Del Loewenthal, 2010). This seems to undermine the core meaning and values that underpin survivors' experience. Van Deurzen (2005) also argues that a person may change their

behaviour with little insight, or that perhaps motivation to change alone may not be enough (*ibid.*, 2005).

The way SCA survivors process information and their cognitions (such as the ability to rate experience and functionality) is viewed through the cognitive behavioural model in terms of symptomology. However, focusing solely on symptoms does not sufficiently explore the phenomenon of the experience of SCA for a particular individual. This means there is no event substantively linked to them, and therefore their feelings and well-being are not seen in the context of their lives. This may make it difficult for survivors to put their suffering into context, and as such they may view it as pathology or in isolation. However, in recent integrative approaches, cognitive behavioural (CBT) and mindfulness-based cognitive (MBCT) therapies have adopted attitudes of 'self-striving and acceptance' and 'walking meditations' from Buddhism (Proeve, 2010). This suggests more emphasis on emotionality and cognitive understanding for SCA survivors, in terms of contextualising outlook and emotional well-being through their responses to surviving SCA.

## **Happiness studies and positive psychology**

Happiness studies and positive psychology focus on positive subjective experience, including well-being and satisfaction, happiness, joy and constructive cognitions about the future, such as hope and optimism (Snyder & Lopez, 2002). In a similar vein to the cognitive behavioural approach, the idea is to enable one to recognise negative thinking patterns and concentrate on strengths, thus preventing depression and anxiety. The emphasis differs, however, which is here on prevention rather than minimising pathology. For SCA survivors, increasing awareness of positive personal traits, social responsibility and creating an outlook on life with a sense of agency (rather than victimhood) may support their transition to greater well-being (Csikszentmihalyi, 1993).

Seligman (2002) argues that a highly heritable personality trait of happiness exists and people operate on a scale, remaining the same over time despite their circumstances changing. In other words, emotions may be changeable, but there is a tendency for individuals to go back to their 'genetic baseline' in their emotional response to life events (Diener et al., 2002). In SCA survivors, a focus on personality, thinking styles and affective happiness may explain differences in emotional reactions and outcome. However, avoiding negative feelings and modifying thoughts accordingly

may allow one to feel less overwhelmed or depressed, but does not mean positive feelings will be replaced (Tantam, 2014). The importance and value base of individual affect seems to be ignored in a drive to focus on what makes one feel better in the shorter term (van Deurzen & Arnold-Baker, 2005). This avoidance, paradoxically, may lead to increased problems in emotional health, where resilience and managing life stressors are not at the forefront of treatment.

Seligman (2002) furthered his work by incorporating humanistic ideas from Maslow (1962). This included self-actualization or personal growth, self-acceptance, purpose, meaning and autonomy as objectives of psychological well-being. These personal elements of growth are important for SCA survivors as they reflect on their experience and assess future goals. How this then translates into their outlook foregrounds their state of emotional well-being. By focusing on positive qualities (in a sense, having constructive cognitions) about the future may help build strength and resilience for survivors.

As mentioned, in SCA studies, ‘subjective well-being’ often refers to how people evaluate the quality of their lives (Diener et al., 2002; Keyes, 2006); for example, the ‘satisfaction with life’ scale (Pavot & Diener, 1993) used to assess life satisfaction and feelings (Iacovou, 2009). The term ‘psychological well-being’, described as *eudaimonic*, an Aristotelian concept of wellness, involves pleasure as the ‘satisfaction scale’ quantifies but also emphasises meaningfulness and growth as a more sustained form of happiness (Bauer, McAdams & Pals, 2008; Jacobsen, 2007). Psychological well-being and subjective well-being, which encompass emotional and cognitive well-being, are terms often used in SCA studies on quality of life that measure wellness via self-report questionnaires. These terms are important, as they express personal survivor experiences and outlook in terms of thought processes, emotional response, attitude and general state of emotional well-being through self-reflection.

## **Humanistic view**

In humanistic psychology, happiness and striving for happiness are important themes. Maslow (1968) claimed that people continue to develop, and are oriented toward either growth or safety in their everyday lives. A growth orientation is more effective in facilitating psychological health and well-being. When considering an outlook from this orientation, one can contextualise SCA survivors as being either focused on moving forward progressively whilst accepting change and

uncertainty in life, or feeling fearful and self-protective. These themes of growth and safety have particular resonance with my population group, who have experienced a major risk to their health and lives. This may shatter their previous sense of safety and challenge prior opportunities for growth. Threats to survivors' emotional health can represent challenges to identity, offering (through narrative) an opportunity for self-transformation.

Individuals who think about their lives predominantly in terms of values such as wholeness, fairness, autonomy and empathy are believed to be on the path to personal growth and well-being (Rogers, 1962). This is important for SCA survivors as it signifies a need to express feelings and emotions openly. In order for one to become a more 'fully-functioning person,' one needs to be more open to experience and the fluidity of change and acceptance (Rogers, 1962), in terms of how the self and personality emerge from experience, rather than experience translating into (and reinforcing) a preconceived construction of the self. In doing so, survivors discuss and accept their responses to the experience, which can in itself be cathartic. This requires recognition of an inner nature, rather than avoiding or suppressing that nature. Unlike the cognitive behavioural approach, emotional expression is not something to be controlled, but rather has validity in its purpose for that individual.

Arguably, when a person is free from defensiveness, they are open to a wide range of their own needs, environmental and social demands and reactions. These can be trusted, are constructive and appropriate (Rogers, 1962). There is thus no need for behaviour modification, as one is open to all experience deemed balanced and appropriate to one's well-being. SCA survivors having an open, authentic and balanced view of their lives requires an assimilation of their historical beliefs, personal attributes and newly-learned behaviours: a deep reflection on what is important for them in life with an added sense of agency and acceptance of limited certainties. However, the humanistic perspective on outlook and well-being seems to make little reference to the social context in which people live and view their lives. How survivors make meaning and ascertain value in their lives is entrenched in their relationship to the world and with others in the world.

## **Existential view**

Personal outlook derives from circumstances that have constituted the life of a person. This is a combination of biological or innate characteristics, parental/caregiver care, early learning and

continual life experience. The culture and beliefs one is born into remain embedded in one's history. This sets the scene as to how one should view and forecast one's life within a social, political and cultural context. In existential terms, these aspects are not seen in isolation from one another, but rather encompass and give context to an individual's entire way of being and existing in a relational world. This means SCA survivors will experience their outlook in ways that are unique to them and that make sense to them in their lives. Their attitude towards the world is often linked with experiences and habits gathered throughout life. These unique viewpoints or biases often express well-being or a particular way of being in the world (Van Deurzen, 2012).

The way this experience translates and how one is able to make sense of it will reflect emotionality. The emotional aspect of well-being expresses what is valued (Van Deurzen, 2012), showing what is felt between one's own particular perspective and the situation encountered. Survivors' feelings and emotions may indicate a particular stance on what they value and what they fear or avoid. The values, purpose and meaning sought through the conflicts of an individual's life are an existential exploration of well-being.

The existential focus is one in which a balanced interaction of possibilities and limitations of life is sought (Van Deurzen & Young, 2009). Arguably, one could say it has particular relevance for survivors of SCA who have first-hand experience of the ultimate dichotomy of life and death. How do they acknowledge and balance uncertainties, difficulties and challenges? Do they deny them in search of all that is happy and positive? Happiness throughout life is certainly possible, but is not at the core of well-being in existential terms. It is authenticity and an openness to strive for what is important to an individual at a deeper level that sits at the heart of the experience of well-being. For survivors, finding meaning and purpose in life can clarify and increase awareness of their choices. These possibilities may enable greater freedom and a sense of autonomy in grappling with their own lived sense of reality.

When one's well-being is disturbed, it can affect all aspects of oneself, giving a more heightened sense of one's own physicality. The body at the centre of each person's existence is also the seat of activities and emotions (Merleau-Ponty, 1962). When one has faced the possibility of death 'head on', unexpectedly and without a known cause, and survived, this may change the perception of how one views reality and one's relationship with mortality: 'When we face up to our death it brings life back into its wider frame' (Van Deurzen & Arnold-Baker, 2005, p. 5). Because we are

always getting closer towards death, Heidegger (1962) argued that by actualizing it as a possibility, we free ourselves from death, rather than losing ourselves. Since SCA survivors have faced death as more than a theoretical possibility, confronting the reality of both human existence and its end.

After a major disruption to their well-being, survivors may need to find meaning once again in their lives. A loss of meaning may create a particular feeling of void or 'nothingness' (Sartre, 1943) which upon deeper exploration may reveal uncertainty around choices, past goals and wishes and even total disconnection from them. This may include a particular state of anxiety around their 'place' as an individual in the world and perhaps their need for purpose and will. For survivors, this may mean taking a closer look at themselves, reconnecting with their values (Strasser, 1999) and finding elements of meaning within a particular cultural and environmental stance that has shaped their value system, attitude and beliefs. However, engaging in meaningful existential exploration may be difficult for some survivors particularly focused on fear of their life ending, self-protection and safety (Maslow, 1968). This may have more relevance at different points in their recovery.

Their relationship with 'self' may involve an acute awareness around reprioritizing what is important to them and how they see themselves in life, such as their particular role and purpose. These existential themes highlight different aspects of a survivor, which encompass their outlook on life and how they are orientated in their world with others. Sartre (1943) argues that by acknowledging the absurdity and meaninglessness of life is, one is able to live better. Through lived experience, a sense of self or a previous version of oneself becomes altered and recreated. The idea here is that with all experience there is an element of learning and transforming oneself via the particular attitude one takes (Frankl, 1988). Through a major life event, many survivors come face to face with the paradoxes in life. For instance, the unexpected nature of SCA, management of a new diagnosis and the uncertainty of recurrence highlight the unpredictability, transience and nonsensical nature of life. They then need to accommodate and make sense of this moving forward. In a sense, SCA has the potential to put a timeframe on one's life.

Using the experiential framework of the 'four-worlds' (Van Deurzen & Arnold-Baker, 2005) enables emotional well-being to be captured through the 'personal, physical, social and spiritual' dimensions of existence. How each person exists, relates to, values and makes meaning out of each dimension contributes to a deeper understanding of overall life experience. This happens



through an exploratory account of how SCA survivors narrate and interpret their stories. The physical aspect refers to how each person thinks and feels about his or her body, its movement, cognitions and any limitations through the physical environment: in effect, how they experience their embodiment.

The social aspect refers to interactions and relationships with family, friends and colleagues who may or may not be experienced as supportive or meaningful. How one relates to others and being in a particular cultural group may allow one to self-define and engage in the world through this lens (Van Deurzen & Arnold-Baker, 2005; Heidegger, 1962). The personal and spiritual dimensions ask how the SCA experience has left them feeling about themselves, their emotional responses, their beliefs and how they have made sense of their experience. Their state of emotional well-being is a grounding or encapsulation of individual survivors' interpretation of experience.

## **Medical Sociology**

Moving away from traditional medical research focused solely on illness and resuscitation, medical sociology adds an important dimension to our understanding of near-death experiences and well-being. It does this through its focus on social and community aspects. It argues that near-death experiences are personal and social crises like bereavement, and should be seen therefore in this context. It is important to understand the social experience of survivors as it directly links to how one then responds (i.e. thoughts and emotions making up the psychological construct of the self).

Illness has the potential to threaten one's social and cultural fabric, thereby threatening self-identity, loss of control (Bury, 1997) and bringing self-worth into doubt (Charmaz, 1983). A crisis like SCA represents stressors for the person and society, and therefore the psychological and sociological are of interest. What may be normal or taken-for-granted for someone in the world then becomes disrupted and displaced, and may need to be redefined (Kellehear, 1996).

A planned future and expectations need to be re-examined after a critical life-changing SCA and can be termed 'biographical disruption' (Bury, 1982). How one then views one's role in life and meanings or knowledge placed on objects is in terms of one's biography and self-concept. SCA may not only disrupt life in the physical sense where limitations exist, but may affect social and

community involvement, relationships and finances. These entwined areas indicate how the effects of SCA can suddenly alter one's life-path. The attempt to normalise after such disruption (*ibid.*, 1982) may depend on available resources in a society, such as the ability to work or receive monetary compensation. This means survivors' emotional well-being is undoubtedly influenced by their perception of available resources and support mechanisms.

Many may feel unsupported by society, where they feel a lack of awareness of their need to readjust to life. This lack of understanding can also arise within their family and friends. When a survivor's familiarity with and trust in the world alters, the environment can become threatening and a sense of alienation or isolation may occur (Kellehear, 1996). This is particularly salient for SCA survivors who belong to a very small percentage of the population. This is reflected in the lack of social and community awareness and knowledge about SCA, and current steps to increase this through sports and defibrillation campaigns. This lack of control is often expressed in their state of emotional well-being by increased levels of physiological stress, depression and anxiety.

It is believed with all transitions that a period of reorientation and then integration into a newly-recognised status is needed, in which one evaluates one's social values, lifestyle, personal and cultural identity (Bury, 1982): the meaning and significance of SCA in regards to an individual's perception of self, as well as how they think others see them. This is in terms of biography, and attempts to repair that after the disruption of SCA by gaining perspective and self-acceptance. Similar to existential and humanistic ideas, it is through overcoming this disruption through narrative and reflection that a person seeks to restore meaning. In a sense, this may have threatened their state of emotional well-being and therefore one needs reintegration and building of autonomy.

## **2.2 Quantitative research on quality of life**

The premise of these studies has been medical. There are a number of validated psychometric assessments used to determine these different components, along with other domains such as life satisfaction. There are also 'un-validated' questionnaires used, which are perhaps more organisation-specific. This variability in method has often been reflected in different outcomes. Emotional well-being shows itself in combination with general well-being characterised by quality of life. This is seen either as a subsection in questionnaires asking about the emotional state,

physical and social dimensions, or in the use of a diagnostic mental health questionnaire to measure symptoms such as anxiety or depression. These studies illustrate how emotions are included when quantifying elements of well-being.

Emotional well-being reported and captured in these studies (under the quality of life bracket) is important for future researchers. It puts into context how the individual and their experience is perceived, whether focusing on symptoms, causes or interrelated factors, such as proving the validity of CPR in a hospital environment to quality of life. These personal judgements in health reveal distress and difficulties, as well as the possibility for further exploration of their experience, which is relevant to this current study's focus on outlook and emotional well-being.

Dobson, Tattersfield, Adler & McNicol (1971) looked at SCA survivors who had an initial heart attack, and this early paper raised awareness around the lack of existing literature on emotional well-being. It appears that after 40 years, there is still minimal research on lived experience of surviving SCA. They argued that because physical prognosis was favourable, more knowledge of how individuals understood their SCA experience and their attitude to long-term adjustment was required. They believed that by focusing on emotional disturbances, unlike many earlier studies, one could see the effect of long-term adjustment to cardiac resuscitation. The starting point was that individual personality traits and personal attitudes affect long-term recovery. This is relevant to this study's focus on outlook, which as previously mentioned consists of individual's personal beliefs and attitudes, combinations of biological and social influences experienced throughout the life course (Van Deurzen, 2015).

Fifteen people underwent an assessment, which highlighted his or her psychological, social and physical adjustment. The methodology used was a combination of the Eysenck Personality Inventory, a self-report questionnaire designed to measure two central dimensions of personality, extraversion and neuroticism (Eysenck & Eysenck, 1965) and the Taylor Manifest Anxiety Scale, a test of anxiety as a personality trait (Taylor, 1953) with an unstructured interview. The unstructured interview focused on attitudes to physical activity, sleep patterns and mood. They found the predominant feelings to be 'disbelief, insecurity, bewilderment, painlessness and closeness to death'. There were no direct questions about their cardiac arrest until it became clear they knew what had happened to them, as at the time medical staff were not informing patients of their SCA, although most became aware by their own assimilation or family's recount.

Using the personality scale above and clustering personality traits in a causal way seems to suggest that a person is 'fixed' in how they are able to adjust to experiences. This appears to reduce and separate the person into components. From this stance, one can infer some association between predisposition and effects on potentially emotive experience, but it may be difficult to predict how people will adapt their responses to the personal experience of SCA. This individual response to experience is often the interplay of many different aspects notwithstanding biology. Further research (Granja, Cabral, Pinto & Costa-Pereira, 2002; Elliott, Rodgers & Brett, 2011; Lundgren-Nilsson, Rosén, Hofgren & Sunnerhagen, 2005; Saner, Rodriguez, Kummer-Bangerter, Schüppel & von Planta, 2002; and Wachelder et al., 2009) has shown the multidimensional aspect of experiencing SCA, in terms of causal outcome and effects on many areas of life. Attempting to separate these in order to find certainty or causal explanation may appear futile, given the wholeness or integration of a person, in which individual aspects co-exist.

Survivors later spoke about having needed more initial hospital support and an opportunity to discuss the experience. This coincides with research (Bremer, Dahlberg & Sandman, 2009; Forslund, Zingmark, Jansson, Lundblad & Söderberg, 2013b) that has shown being able to piece together what happened and increase knowledge of SCA can help survivors create a sense of meaning. This may have contributed to responses of uncertainty, fear and initial anxiety presented by all survivors, particularly as their statistics showed that half of all participants had a moderate pattern of adjustment during the first few months, although poor long-term adjustment was also associated with more initial anxiety and depression linked to greater physical disability. This highlights the interlinked areas of 'the self' embodied through the physical, social and psychological aspects, which are recreated particularly through the experience of illness and dying. The 'conscious self' is constantly remodelled through one's own lived experience (Sartre, 1943). As we have seen, existential ideas emerge also in quantitative research and offer some context to the deeper understanding of individual (symptomology) and experience.

Granja et al. (2002) focused on functionality 6 months after hospital discharge in order to measure the quality of life after cardiopulmonary resuscitation (CPR). They conceptualised quality of life as multidimensional and therefore concentrated on 'health-related quality of life' to include one's mental and physical state as well as one's own sense of well-being, importantly. To capture this,

they used the EQ-5D health questionnaire, (The EuroQol Group, 1990)<sup>3</sup> a 5-dimension scale, to ask people to rate themselves in terms of mobility, self-care, usual activities, pain, discomfort, anxiety and depression on a scale ranging from ‘not at all’ to ‘extremely’. Over a period of 6 months, 19 people participated.

They found a higher percentage of people reported more extreme problems in some dimensions compared to the intensive care control group. These were mainly those with increased cognitive deficiencies, showing how limitations in one area are reflected in another and affect overall well-being. This study is important as it shows how decreases in cognitive ability after SCA can affect emotional health and well-being in terms of how one feels about oneself and life in general. Although no statistical differences were found between SCA survivors and intensive care patients, there were self-reported struggles among these participants. Individual feelings and emotional responses, which are related to anxiety and depression in a sense, may be difficult to evaluate where answers are pre-determined, rather than have the person express their thoughts in their own words. Choosing an answer from the three scale points provided may not accurately represent a person’s well-being and provide a broad measure of comparative groups only (similar to other psychometric tests). One could argue that when thinking becomes ‘ordered acts’ that ‘actualities are accepted as given they become conceptually determined’ (Husserl, 1913 p.69), with minimal expansion.

Granja et al. (2002) also state that ‘health-related quality of life can be conceived as a subjective concept, primarily reflecting individual patient attitude’ (p. 38). It would appear that an individual’s attitude may be difficult to be expressed through the format of questionnaires. Heidegger (1962) also argued it is only through a proper examination of what appears, and seeking meaning and interpretation of experience, that what an event or change has meant for someone reveals itself. Arguably, it may also be more difficult to self-assess emotional well-being given existing cognitive and physical deficiencies or limitations. Nonetheless, this study is important as it gives an indication of individual attitudes towards physical and emotional well-being captured by self-reports or questionnaires. It also demonstrates that assessing quality of life is complex, particularly for SCA survivors who may have experienced changes in many areas of their lives.

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<sup>3</sup> Trademark of the EuroQol Group used to measure quality of life in health-related research.

This is demonstrated also by Lundgren-Nilsson et al. (2005), who set out to assess life satisfaction in an attempt to capture a more general sense of quality of life (their primary focus was on physical and cognitive functionality as a precursor to quality of life and well-being). It commenced with 26 people who underwent a longitudinal assessment after 2 weeks, 45 days, 3 months and 1 year. They used the Nottingham Health Profile (NHP) questionnaire, which measures physical mobility, pain, sleep, social isolation, emotional reactions and energy levels (Hunt, McKenna, McEwen, Williams & Papp, 1981) to assess their health-related quality of life. With their focus on physical health, they found improvement during the first year. Individuals doing well improved greatly from the first assessment, especially regarding physical mobility, emotion and sleep reporting, while those with problems in daily living had reduced cognitive function and life satisfaction. How someone rates their satisfaction with life impacts on their outlook and how they conceive their future. Unsurprisingly, many who struggle with reduced physical and/or social abilities (with more life changes in different spheres) will experience and report more difficulties in emotional health. This questionnaire has a small section on emotions and energy levels, which was the only information sought specifically on emotional or psychological health.

Along similar lines, Wallin, Larsson, Rubertsson & Kristofferzon's (2014) study concluded that more than half of participants had a prior illness, which may have influenced their personal ratings of health-related quality of life. Their existing illness had affected a perceived sense of well-being after SCA, which compounded previous stressors (Rosman et al., 2015). There were differences in methodologies and a variety of questionnaires were used namely EQ-5D (The EuroQol Group, 1990), the hospital anxiety and depression scale (HADS) detecting states of depression and anxiety in the hospital setting (Zigmond & Snaith, 1983) and the Short-Form Health Survey (SF-12), assessing physical function and mental well-being (Jenkinson & Layte, 1997). These may have contributed to the variation in results. Using the questionnaires with 26 survivors up to 6 months post-arrest, they sought to measure the relationship between anxiety, depression and health-related quality of life. They found a negative correlation: when individuals perceived themselves as less anxious and depressed, their overall quality of life scores increased. They discovered this effect to be the strongest at 6 months, suggesting an improvement over this time-span. However, anxiety and depression calculated via HADS showed no significant change over time, apart from a decrease in those initially displaying a higher score.

Although these two studies by Lundgren-Nilsson et al. (2005) and Wallin et al. (2014) are dominated by physical and cognitive functioning, they raise the question of using either the term 'health-related quality of life' or 'quality of life', defined by the World Health Organization (WHO, 2001) as including physical, psychological and social aspects. As both terms encapsulate some aspect of emotional health, they potentially contribute to the variety of methodologies, which then inform experience. One set of authors asks 'why the survivors of cardiac arrest appear to have such poor life satisfaction' and believe the answer is to be found via qualitative interviews (Lundgren-Nilsson et al., 2005). This suggests that these less common areas of study, such as attitude, emotional wellness and satisfaction, are indicative of a more exploratory approach, which is less formulaic or questionnaire-based. One could also argue that assessing satisfaction and well-being after a sudden threat of mortality may require further engagement and reflection on one's life.

Moulaert, Wachelder, Verbunt, Wade & van Heugten's (2010) study of 63 survivors also revealed significant correlations between quality of life, daily activities, severity of fatigue, a number of cognitive complaints, and the level of mood disturbance: depression, anxiety and degree of post-traumatic stress. They took a holistic approach to analysing the factors composing quality of life in this population group by studying the effects of experience in terms of cognitive complaints, fatigue, anxiety, depression, posttraumatic stress and difficulty in daily activities. In doing so, they contextualised a clinical rehabilitation programme addressing these elements. Their aim was to identify factors that influence how quality of life is experienced, and found cognitive and emotional functioning contributed to this. Like other studies, they discovered that cognitive complaints and fatigue were linked to both physical and mental health: post-traumatic stress contributed to the physical quality of life, and anxiety and depression affected only mental quality of life. The importance of this study lies in not only showing the multiple factors which co-relate in survivor experience, but also addresses them through a clinical programme showing the main influencers.

For my current study, this suggests that linking different areas of physical and psychological health and considering how each influences the other enables one to contextualise quality of life or physical and emotional well-being. In the treatment sense, this might allow one to consider individual elements in relation to the whole person. However, one could argue that adopting a

medical stance, defining emotional experience by difficulties and consequences, shows little of a person's story; how they have made meaning from it; or how they might have assimilated that experience. In the same way, it has been argued that 'the author can be really understood only by going back to the origin of the thought' (Schleiermacher, 1998 p.192). This suggests a need to understand the personal experience from the viewpoint of an individual who then becomes a SCA survivor. Focusing entirely on controlling symptoms or uncomfortable feelings may provide only a superficial understanding.

Along a similar line, Saner et al.'s (2002) study aimed to quantify the outcomes of CPR. Long-term quality of life was measured in 50 individuals with a mean age of 60, and post-arrest time of 2.6 years compared with a healthy population. They used four self-rating questionnaires including a Self-Assessment Test, the NHP (Hunt et al., 1981), the Psychological General Well-being Index (PGWBI), measuring an individual's feelings about their inner personal state (Chassany, Dimenäs, Dubois, Wu & Dupuy, 2004). Lastly, the Everyday-Life Questionnaire (ELQ), measuring health-related quality of life in physical, emotional, social and functional components and joy of life (Bullinger, Kirchberger & von Steinbuchel, 1993). This was to measure physical and emotional disturbance, social and functional aspects covering well-being and life satisfaction, pre- and post-SCA. It is important to include this study as it shows how emotional well-being (as well as the social and physical) is captured through the above tests. Interestingly, and similar to previous studies, the results varied depending on the tools used. The NHP revealed significant decreases in emotional reactions, energy levels, physical mobility and sleep. However, the PGWBI showed no significant within-group differences in levels of anxiety, depression, well-being, vitality, self-control or general health, but did so when compared with a healthy population.

There were no differences in how participants viewed themselves before and after the SCA. This study shows the variability of outcomes based on questionnaires and definitions used, and in how they are applied. For example, separating one area of 'being' from another, seeing it in isolation and compartmentalising experience around symptoms, may make it difficult to put it into context and integrate a unified sense of well-being. However, the authors conclude by proposing the use of a combination of validated health questionnaires, although there are no proven clinical criteria identifying people who are likelier to survive. This suggests uncertainty in terms of predicting survivor outcome, and perhaps less rigidity in conforming with self-reports.



The studies above by Lundgren-Nilsson et al. (2005) and Saner et al. (2002) compared survivors with a healthy population group. This suggests there is a normative measure. When comparing emotionality, including a rating of feelings and affective states linked to the experience of their SCA, it is clear the control group did not share a traumatic experience. It may be fairer to compare the SCA group to another group of patients who had experienced another form of trauma, rather than to a group of healthy people. The experience itself seems overlooked in a preference for isolating symptoms and perhaps comparing those to a group deemed in the normal range. One could argue there would be variability in most groups, taking into consideration the individuality of people and their emotional and mental health. Saner et al. (2002) acknowledge this, stating, 'Generally, quality of life indicates subjectively experienced woes or well-being which may be difficult to measure' (p.11). This indicates the need for further qualitative studies.

Rien de Vos, Hanneke, de Haes, Koster & de Haan (1999) also focused on CPR and personal characteristics. These traits in participants were looked at before, during and after their arrest. Quality of life was investigated in 90 individuals who completed four questionnaires namely the Sickness Impact Profile (SIP) measuring quality of life (Bergner, Bobitt, Carter & Gilson, 1981), the Mini-Mental State Examination (MMSE) measuring cognitive functioning (Folstein, Folstein & McHugh, 1975), the Epidemiologic Studies Depression scale used for the general public (Radloff, 1977) and the Rankin Scale for neurologic disability in daily living (Rankin, 1957). They found 75% of SCA survivors were independent in daily life and rated their quality of life as seven out of ten, although 16% showed depressive symptoms. It was revealed those over 70 had more impaired quality of life, and differences in heart conditions had an impact on recovery. They concluded that quality of life after CPR was determined by factors known before CPR and the reason for admission to hospitals, such as age and diagnosis.

Similarly, Wachelder et al. (2009) revealed that 60% of participants had a history of cardiac conditions that contributed to poor adjustment. They focused on SCA survivors having lower levels of functioning in all domains in comparison with the general public. They tested this using a myriad of questionnaires including the 36-item Short Form Health Survey (SF-36) measuring quality of mental and physical life, covering eight dimensions of health (Ware & Sherbourne, 1992), HADS (Zigmond & Snaith, 1983), The Impact of Event Scale (IES), a 15-item questionnaire used to assess stress reactions after traumatic events (Horowitz, Wilner & Alvarez,

1979). Also, the Fatigue Severity Scale (FSS), a nine-item questionnaire used to assess the impact of fatigue on patients' functioning (Kleinman et al., 2000), the New York Heart Association Classification (NYHA) used to classify cardiovascular disability (Fisher, 1972) and the Cognitive Failures Questionnaire (CFQ), a 25-item inquiry into failures in quality of life, participation in society, and physical, cognitive and emotional impairment (Broadbent, Cooper, FitzGerald & Parkes, 1982). They found after 3 years, 74% (of 63 survivors) had low participation in society, which they believed was related to their age. They also found that over 50% had severe fatigue; 38% had feelings of anxiety and/or depression; and 24% reported decreased quality of life. This study showed mixed results and used a variety of self-reports as well as elements of underlying illness, impairments, age and the many other variables at play.

The above studies (Rien de Vos, 1999; Wachelder et al., 2009) reveal how age and prior illness have a compound effect on someone's quality of life after SCA. It is important to highlight this for its relevance to this current research, in which age and prior illness have been restricted in order to focus on the phenomenon affecting a younger and presumably healthier population. This is also similar to Saner et al. (2002), in which 40 of their 50 patients were diagnosed with a heart disorder. The individual's experience consists of many factors affecting how they interpret their own sense of well-being. One could argue that, nonetheless, better outcomes could be achieved even with the most resilient patient with more emotional post-support. In this sense, quality of life is inextricably personal.

### **2.3 Treatment with Implantable Cardioverter Defibrillator (ICD)**

Addressing the literature from an ICD treatment angle is important because it can play a substantial role in the SCA experience and affect psychological and emotional well-being. Many individuals diagnosed with arrhythmia following arrest are at risk of recurrence and likely to have an ICD. The constant physical reminder of this device may affect one's emotional health, creating more stressors. There is the potential that sustained worry can act as a precipitant to ventricular arrhythmias (Pedersen, van Domburg, Theuns, Jordaens & Erdman, 2005), in which each can have a negative spiralling effect on the other. These individuals need to manage their stress levels (Vlay & Fricchione, 1984) and current research suggests outcomes are variable. Relevant studies considered the ICD device itself affecting emotionality; the susceptibility of those with more anxious temperaments; existing emotional difficulties; and experiencing another arrest with the

device firing.

Sears, Todaro, Lewis, Sotile & Contie (1999) reviewed the psychosocial impact of an ICD in terms of an individuals' psychological distress, quality of life, social and role functioning in 22 studies. They compared three groups: those without ICD discharge, those with discharge and those whose treatment was not ICD. They found no differences between them on measures of anxiety and depression. Despite 75% reporting high acceptance and seeing it as a security measure, ICD-specific fears and clinical anxiety showed up in 38% percent of participants. Over half had trouble sleeping and had depressive symptoms, while just under half displayed fear around shock, device malfunctioning, sexual activity triggering charges, pain, loss of control and death. Anxiety levels were significantly higher in those who had experienced ICD discharges when followed up after 12 months. Having experienced one or more discharge was strongly associated with anxiety, depression and health concerns. They concluded that younger people and those with high discharge rates had more adjustment difficulties. Nearly everyone, however, reported an increased preoccupation with his or her cardiac condition since implantation.

This study reveals that, statistically, quality of life is good, although higher levels of fear, anxiety and depression are evident in individuals with an ICD, particularly those who have experienced at least one shock within the first year. This increased awareness of, and mental and physiological distress around, the implantable device is an increased element of survivor experience and hence important and relevant to my study. This undoubtedly affects their cognitive responses, thoughts, feelings and outlook with an increased sense of threat to life. Sears et al. (1999) argue that other variables like psychological history and poor social support play a part in life stressors and psychosocial adjustment. Indeed, there are many aspects related to individual response. How a SCA survivor remains affected by and responds to an ICD is a combination of their personal and social experience. This allows variability in outcome, creating causal uncertainty but also expresses how one feels and experiences one's world. This study highlights the increased risk for survivors who may feel a constant awareness of their ICD, precipitating fear of further arrests affecting their well-being.

A longitudinal study by Dunbar et al. (1999) looked at the association of mood disturbance, emotional status and arrhythmia events after ICD. They wanted to see whether emotional states relate to subsequent arrhythmia, in individuals at high risk of recurrent ventricular arrhythmia. 144

men and 32 women with a mean age of 60 participated in the Profile of Mood States (POMS) questionnaire (McNair, Lorr & Droppleman, 1993) before implant and at 1, 3, 6 and 9 months afterwards. By the first month of follow-up, 35 participants had an arrhythmia, 35 by 3 months, 32 by 6 months and 23 by 9 months. The results showed those with arrhythmia events had higher total mood disturbance scores throughout the 9 months of follow-up. There was a higher level of mood disturbance, including anxiety, fatigue and confusion at 1 and 3 months, which, after discounting other variables, suggested independent predictors of subsequent arrhythmias at 3 and 6 months.

There were also no differences in scores before and after ICD shocks, suggesting that negative emotions were a cause rather than a consequence of arrhythmia events. In other words, mood disturbance may precede arrhythmia, and ICD shocks appear to have little impact on overall mood disturbance. This study reveals a different approach, methodology, focus and outcome. Interestingly, it shows that the device itself can increase difficulties, regardless of whether people receive a shock. This study also shows how important it is for emotional well-being in that concerns and uncertainties over the device need constant management throughout the life course. Survivors' responses and emotions are important to the individual and their life experience. Insofar as this device is there to protect their physical health, it is for some an undesired extra element, increasing health concerns.

This study by Dunbar et al. (1999) is important for my research question as it addresses a very important aspect of surviving SCA. Many survivors have the ICD implanted as a precaution, but fear, anxiety and stress can be created and have serious consequences for their emotional well-being. From an existential perspective, this highlights the continual stark confrontation with life and death, and the explicit negotiation between uncertainties in their lives and balancing limitations (fears) with possibilities of existence. One could suggest an attempt at improving clarity in their personal values and life meaning. Strasser (1999) also states, 'Meaning is interconnected with our values, our aspirations, and our strategies for survival' (p.16).

However, another study found differing results. Kamphuis, De Leeuw, Derksen, Hauer & Winnubst (2002) conducted a study assessing the quality of life and well-being in 168 survivors who received treatment of an ICD, compared with 35 who received medication or surgery. Their aim was to see how people adjust psychologically to their condition and its treatment. They used

several questionnaires including SF-36 or RAND-36 (Ware & Sherbourne, 1992) to measure the quality of life, the Heart Patients Psychological Questionnaire (HPPQ) for psychological well-being (Visser et al., 1995), the State-Trait Anxiety Inventory (STAI) for anxiety (Marteau & Bekker, 1992) and the Epidemiologic Studies Depression scale (Radloff, 1977) for depression. All participants undertook them during hospitalisation and at 1 and 12 months post-discharge, including before implantation.

They found there were no differences between groups on the above measures. The quality of life and well-being did not change significantly over the year, although those with higher anxiety made fewer health improvements and showed depressive symptoms and poor social function. Both groups displayed distress and higher levels of anxiety and depression, which continued over the year. Since the quality of life improved for all after 6 months, they suggest that it may be the relief of surviving the event itself that has a greater impact on well-being, rather than the type of treatment. However, there is a noticeably large difference in the size of the two groups, which may skew the results. This study shows those with earlier difficulties, regardless of treatment, continued to have poor symptoms. This is important for emotional well-being, as it shows that although medical treatments have considerable impact, they are not the only factor when assessing quality of life.

Another study by Kamphuis, De Leeuw, Derksen, Hauer & Winnubst (2003) assessed quality of life and psychological well-being over the course of a year in those who received shocks from their ICD and those who did not. Importantly, their aim was to see how receiving shocks affected the level of adjustment to an ICD. These same four questionnaires were given to 167 people before implantation and at 1, 6 and 12 months after hospital discharge. They divided participants into four groups: those with no shocks, a shock after 6 months, a shock at 3 and 6 months, and two shocks. The control group had no ICD implanted.

The results showed that 26% received a shock during the first year, and 6% had more than three shocks. Those who had a shock in the first year, particularly in the first 6 months, were more anxious and showed more anxiety and depression at 12 months. This shows that continual emotional support was necessary. They also reported poorer quality of life, especially those who had a shock in two periods, although overall it did not change significantly between 6 and 12 months in any group. They became less anxious with time when they had not experienced a shock

in the first year.

Kamphuis et al. concluded that actual shocks influence quality of life, rather than the choice of treatment or device, interestingly. They state, 'Psychological distress does not dissipate over time' (Kamphuis et al., 2003, p. 387) and therefore more therapies are required. This contrasts with the findings of Pedersen et al. (2005) in which the concerns participants had about their ICDs were not related to the number of shocks received. Separating treatment into shocks and their effects will inevitably have more impact on well-being due to the experience of further threats to life. However, the ICD treatment as a whole and what it represents in terms of potentialities and sustained uncertainties may be more difficult to measure over time. In comparison to those with other implantable devices such as pacemakers, those with an ICD are always aware of the unpredictable nature of the device and its potential for discharge (White, 2002). This added element of a survivor's experience needing management throughout life often contributes to further worries and emotional disturbance.

Existing studies also show a gap in qualitative research around living with an ICD and the subjective lived experience of survivors. This is not just in terms of outcomes, such as having to decrease stress levels, or causal, such as having a particular personality trait, but rather the affective experience is under investigation.

## **2.4 Quantitative research on anxiety, depression and posttraumatic stress disorder in SCA survivors**

As previously mentioned, in healthcare, symptoms relating to anxiety and depression are usually indicators of emotional or psychological well-being. A small amount of research has focused primarily on the pathology of psychological effects on SCA by measuring post-traumatic stress disorder (PTSD) symptoms, depression and anxiety. The studies below suggest high levels of psychological distress, particularly phobic anxiety and panic symptoms, in the early stages, although methodological variability is typical.

Schaaf et al. (2013) evaluated existing studies and their methodologies in order to address the clinical implications of psychological distress affecting survivors post-arrest. With the majority of research focused on medical outcomes, they believed it necessary to redirect attention to

psychological concerns, and particularly patients' psychological condition; not through the broad construct of quality of life (perceived to be superficial), but rather separately, in relation to pathology and diagnosis through the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). Using a comparison group of people with other cardiac experiences (such as stroke or heart attack) with many post-affective studies, they sought broader knowledge in regards to linking mental health disorders and cardiac arrest. Importantly, they endeavoured to widen knowledge around possible outcomes of SCA.

They used studies measuring anxiety, depression and PTSD using the Beck Depression Inventory, a 21-item, self-report rating inventory measuring characteristic attitudes and symptoms of depression (Beck, Steer & Brown, 1996) and the HADS (Zigmond & Snaith, 1983). These studies report widely varying estimates of the prevalence of these conditions in the past 20 years, ranging from 14%-45% depression, 13%-61% anxiety, and 19%-27% PTSD. These variable results are believed to stem from variations in methodology. The studies show that psychological distress is a clear problem, although with no standardised methodology there is little consistency in their assessment. According to this review, one in four SCA survivors experience anxiety, depression or PTSD. The above study puts back into focus the importance of emotional adjustment for survivors of SCA. It highlights the importance of long-term outcomes, particularly how emotional and mental health can be challenging for some survivors who struggle to cope. To suggest some individuals need more emotional support after a near-death experience reflects changes in increased survival and long-term outlook relevant to the current study. This narrative shift acknowledges the experience of SCA as a traumatic and life-threatening event, which for some people may elicit higher levels of stress and unease.

They conclude by stating that more studies are necessary of longer-term post-SCA survivors and their susceptibility to distress. This study also shows how important it is to focus on SCA and its pervasive impact on survivors' outlook and well-being. This has a particular poignancy for my current study. The combination of personal experience and symptomology enables a situated perspective (Merleau-Ponty, 1962), showing how each person relates to the world in their own way.

A study by O'Reilly, Grubb & O'Carroll (2004) looked at the long-term emotional consequences of cardiac arrest. As they found prevalence rates for PTSD in research to be 10% after myocardial

infarction (MI) commonly known as heart attack, they sought to find comparisons in those whose MI led to a SCA. Their aim was to compare the prevalence and severity of emotional disability in both groups using the HADS (Zigmond & Snaith, 1983) questionnaire and to assess for symptoms of PTSD in a Structured Clinical Interview for DSM-IV (SCID) (Ventura, Liberman, Green, Shaner & Mintz, 1998). A sample size of 27 survivors after 5 months revealed higher levels categorised as 'clinical anxiety and clinical depression' via DSM-IV. The figures were 30% for anxiety and 15% for depression, compared to 2% and zero in the MI-only group. The depression scores were significantly higher, which supported their hypothesis of emotional maladjustment being higher and more severe in SCA survivors.

The above study highlights that a significant portion of people experience emotional distress. Again, it recognises the need for more research on survivors and their long-term emotional and psychological well-being. This study is important because it not only focuses on emotional and psychological health, but also differentiates between those who had a SCA and those who had a heart attack. This suggests prior illness in the latter group. While a smaller percentage of people have a SCA suddenly without knowledge of existing illness (my target population), it is relevant to show this difference for my current study. As O'Reilly et al. (2004) have shown, SCA survivors without prior illness can be susceptible to increased emotional maladjustment.

This study also shows stronger support for PTSD than for general emotional distress. Statistically, however, both groups are likely to suffer PTSD despite cardiac arrest being a more life-threatening event. They believe that SCA survivors are at a greater risk of developing avoidance symptoms, leading to persistent problems, which relate to PTSD. Arguably, during SCA most individuals lose consciousness immediately, so they are not experiencing the event as it unfolds. Consciousness being embedded (or felt) in the body shapes what we know about the world (Merleau-Ponty, 1962). Hence, one may feel disconnected once informed of their SCA if there has not been an embodied experience of mind and body recollection. This may make it easier to disengage and reject experience. A personal and detailed account may allow the person to put their experience into context.

O'Reilly et al. (2004) also showed inconsistencies, particularly in those displaying symptomologies in PTSD symptom assessment where disclosures in interviews did not match self-reports. This lack of agreement between interview and self-report diagnoses perhaps again reflects the use of



diverse measures. They acknowledge that they ‘can’t be certain PTSD relates directly to the SCA experience, the resuscitation procedure, both or knowledge of surviving a near death experience’ (p.92). This suggests the ‘SCA experience’ being further narrowed; for instance, to feelings about resuscitation or having survived death considered as individual components, rather than entwined in the fullness of one’s experience. This may make it challenging to gain an understanding of emotional well-being when the personal experience lacks wholeness.

Gamper et al. (2004) also found that over an 8-year period just under a third of 143 people fulfilled the criteria for PTSD using the Davidson Trauma Scale (DTS), which is a 17-item self-report measure that assesses all primary DSM-IV symptoms of PTSD, resulting in a significantly lower quality of life (Davidson, Tharwani & Connor, 2002). The only independent risk factor for PTSD identified was younger age. Similarly, Ladwig et al. (1999) looked at emotional disability and PTSD symptoms, namely recurrent and intrusive thoughts, in 21 MI survivors with or without SCA after 3.3 years. They found that SCA survivors had higher levels of intrusive thoughts and avoidance (38%) using the Impact of Event Scale. Using the HADS (Zigmond & Snaith, 1983), they found 75% of SCA survivors in the normal range for depression and anxiety resulting in high levels of emotional stability and well-being. The remaining 25% were in the moderate to severe range, reflecting their higher scores for PTSD. They concluded those with higher levels of intrusion failed to integrate their recollections of the SCA experience, resulting in an impaired quality of life.

These studies reveal how varied the adaptive qualities underpinning each person are when it comes to particular experiences. Another study discussed the idea that predictors of PTSD in cardiac arrest survivors had personality traits, such as a repressive coping style and type D personalities, with a tendency towards negative affectivity, perception of threat to life, fear, illness comprehension, dissociating from the event and history of prior trauma (Tulloch et al., 2014). It is important to capture emotional well-being in SCA survivors from different angles, since its complicated nature affects people not only differently, but has many variants. Gamper (2004) noted that emotional disability was the same for both groups, although SCA survivors demonstrate higher avoidance and intrusion levels, typifying PTSD symptoms (as in O’Reilly, 2004).

Varied and contradictory results seem almost inevitable when measuring psychological stressors

like PTSD, depression and anxiety, given the various tools used. There also seems to be a lack of consensus in defining these clinical terms using psychometric tests and perceived cut-off points for diagnosis. Nevertheless, these studies highlight the importance of distress and emotional well-being in long-term SCA survivors. They recognise the significance of surviving SCA as a unique and life-threatening phenomenon, with a small amount of existing psychological research to date, compared with their MI counterparts. Given this complexity, SCA survivors may require more adjustment to reach a healthier state of emotional well-being.

A recent study done by Rosman et al. (2015) looked at the effects of repeated exposure to trauma in SCA survivors as a compound risk. Half of their 188 participants reported previous exposure to trauma where they reported intense feelings of fear and helplessness, and 25% reported a traumatic stress response to a historic trauma. They concluded that it was an individual's report of a traumatic stress response that related to clinically significant PTSD and more severe symptoms after SCA. Similar to Gamper (2004), they also stated younger survivors were significantly more likely to experience PTSD symptoms after SCA, reflecting perhaps interpersonal factors such as fewer emotional, social, and financial resources. This is significant, since my target population is under 60 years of age. Importantly this study also reveals another angle to experience and well-being in which compound effects of multiple trauma, severe stress and fear can further increase emotional maladjustment in survivors. This adds to the varied dimensions of lived experience. These important elements in existing research are included to show variable states of outlook and emotional well-being being captured through different methodologies.

## **2.5 Qualitative research on making meaning out of the experience of SCA**

These studies are important as they focus on individuals' subjective experience and the phenomenon of SCA using qualitative methodology. Like my own study, their focus is on the ontological concerns of individuals, studying how they experience the world, rather than primarily focusing on ontic responses or symptomologies (Heidegger, 1962). Significantly for my study on outlook and emotional well-being, they explore how people interpret their lives and the importance and meaning placed on life events. One can argue that meanings help shape future goals and affect one's outlook (Park & Gutierrez, 2013). I will discuss the few relevant studies that

capture an individual's story and elucidate 'meaning-making' in particular.

Forslund, Lundblad, Jansson, Zingmark & Söderberg (2013a) conducted a mixed design study (including qualitative content analysis) that looked at psychosocial risk factors in people who suffered MI, which led to SCA. 60% had no previous knowledge or earlier diagnosis of a heart condition. The factors studied were socioeconomic status, anxiety, depression and work overload. The qualitative section gave questionnaires to 32 people, of whom 15 were interviewed. The interviewees had a mean age of 68 and post-arrest time of 8 years. The questions asked what lifestyle meant to them and what was important to make them feel good.

The focus of this study was on preventative measures and is reflected in their usage of terminologies such as 'lifestyle' in reference to relationships, meaning, motivational changes and outlook. The main themes found were 'significance of lifestyle' (meaningful relationships); 'modifying current to new life situation' (finding reasons why it happened); and 'making changes and a changed view on life' (feeling grateful for a second chance). These themes are important for this current study as they reveal how personal and social influences come together in terms of one's outlook on life. All participants believed negative work stress had contributed to their SCA.

The above study revealed what meaning participants placed on their experience. Importantly, this was then reflected in how they envisioned their life moving forward in terms of self-management, life choices and positive outlook. Paradoxically, they found that although many knew the risk factors and benefits of treatment, including behavioural changes, some chose to ignore this information, preferring to live a 'good life'. This suggests that some of these participants were exerting their choice and autonomy pre- and post-SCA, making a deliberate decision about how they wished to live. However, in this study, with its focus on morbidity, the notion of 'living a good life' differs in context to that of the effect of SCA. It does not account for the experience of SCA, although still relevant to the current study as an outcome of existing illness and thought around lifestyle choices.

Another similar study by Forslund et al., (2013b) interviewed 11 people with MI aetiology and used structural analysis, following Ricoeur's phenomenological hermeneutic methodology. The aim was to highlight any meaning created out of their experience. Participants talked about what happened when they became ill, what they remembered and how they live life today. They

discovered that it was important for participants to be able to express verbally and in dialogue what had happened to them, as opposed to one-way conversations they had in the hospital. This notion was also reflected in other studies (Dobson, 1971). They expressed the need to search for an explanation as to why it happened, to seek motivation around the recovery process and to talk to healthcare professionals. The main themes that emerged were 'returning to life' and 'revaluing life'. The subthemes included 'waking up and missing the whole picture', 'realising it was not the time to die', 'wondering why and seeking explanations', 'feeling ambiguous in relationships' and 'wondering whether life will be the same'.

They found that the event made them re-evaluate what was important to them in life. Importantly for well-being, they stated, 'The presence of a life-threatening illness can interrupt a person's time flow and make him aware that everything has changed' (Forslund et al., 2013b, p. 6). This study shows how important it was for survivors to talk about their experience in detail. There was a need to assimilate and make meaning out of what happened and move forward in life. Looking for an explanation and building meaning from the event may help in rebuilding a sense of control and outlook. One can argue from an existential viewpoint that 'we are temporal beings in time' (Heidegger, 1962), meaning that individuals find meaning in the temporality of their existence. These important themes around meaning and making sense of an experience are particularly important to my study, as it is through these self-reflections and reassessments that survivors' view of or take on their lives can be captured.

Similarly, Bremer et al. (2009) did a phenomenological study and found that well-being became discoverable through a sense of coherence and making meaning in life. The individual, upon awakening from SCA with memory loss and little sense of time or coherence, may experience a feeling of threat, needing to piece together and make sense of what happened. This study is significant for its focus on the subjective experience of out-of-hospital cardiac arrest, as well as the SCA phenomenon itself, and how it influences well-being over time. This includes how individuals made sense of their experience using lifeworld phenomenology and reflective analysis (Todres, Galvin & Dahlberg, 2007) through being body subjects or embodied individuals: a descriptive (rather than interpretive) look at the indivisible interaction between individual personality and how it encounters the social world. This focus on an individual perspective was to gain more information about personal wishes, care and autonomy and allow self-determination for this group

in healthcare.

They conducted semi-structured interviews with nine survivors aged 44 to 70 years, most of whom had their SCA within three years. Interviews were analysed for meaning through the description of experience and focused on ‘coherence’ and ‘memory gap’. This reflected an altered sense of time, and how significant memories were linked to the present. The ‘elusive life-threat’ becomes comprehensible through an increased understanding of its occurrence, enabling existential security and well-being (Bremer et al., 2009). Arguably, their future vision or outlook is only imaginable through being able to make meaning and seek coherence, particularly after a major life event of SCA. Thus, a more coherent awareness is formed where the gap in memory symbolises the cardiac arrest itself.

Interestingly this study highlights the symbolic reference to conscious time and being in time and the implications these have for lived experience. For example, a survivor loses consciousness when their heart and vital signs of life stop, and only through reversing this is their life saved. This disordered sense of well-being around time may be linked to what understanding, value, reason and meaning (Bremer et al., 2009) is placed on their survival. They found ‘accepting what had happened’, ‘redefining their life’ and ‘having experienced their own mortality’ to be dominant themes. It was important how one viewed one’s life progressively. This study shows how self-interpreting experience and finding acceptance and meaning in SCA contributes to outlook and emotionality.

This follows a similar study by Ketilsdottir, Albertsdottir, Akadottir, Gunnarsdottir & Jonsdottir (2013) focusing on the experience of the cardiac arrest itself, as opposed to other factors resulting from this experience, such as underlying disease, ICD implantation and quality of life. This ‘general’ investigation of the experience of SCA is important here, as it recognises the phenomenon itself. Their aim was to gain knowledge of the effects of experience by looking at the unique concerns and needs of survivors following SCA and resuscitation. Using interpretive phenomenology, the analysis drew on the five sources of commonalities in lived experience: situation, embodiment, temporality, concerns and common meanings, until themes without contradictions were developed. Seven survivors up to 2 years post-arrest answered questions describing their experience and what effect it had on them in two semi-structured interviews. The second interview enabled further discussion of interpretations made in the first interview for

added validity. The meaning of this experience lay within the historical, social and cultural context of the participants' lives.

The results revealed themes including 'feelings of insecurity; the need for support; striving to regain a former life; emotional challenges; responding to symptoms and a new view on life'. Cognitive limitations, anxiety, lack of security and uncertainty regarding the future were participants' main concerns. Conducting two interviews to discuss further interpretations may have allowed additional insights and reflection. These concerns are similar to those found in the above studies and highlight individual worries around emotional support and a need to re-establish a somewhat different outlook. This study importantly addresses the historical, social and cultural elements of an individual when looking at the phenomenon of SCA, suggesting a deeper exploration of lived experience.

These few qualitative phenomenological studies originate mainly from Sweden and Iceland. They have attempted to capture the phenomenon of SCA through meaning-making, using similar methods to IPA. They have attempted to show validity in self-reports that indicate an expression of survivors' lived experience in a detailed narrative account. The intention was to explore and understand personal experience in order to ascertain what their needs and clinical support may be post-hospital treatment. In my study, I endeavour to continue along this line of phenomenological exploration, showing meaning-making whilst integrating outlook and emotional well-being.

### **3 METHODOLOGY**

In order for me to explore outlook and emotional well-being in survivors of sudden cardiac arrest, I needed to select a method of enquiry that would allow me to collect rich, detailed descriptions of participants' narrated lived experience. Interpretive Phenomenological Analysis (IPA) is used and discussed below, but first, I will enquire into the philosophy behind the method. The methodology is informed by my epistemological position (i.e. what we know and say about the world). This begins with a certain paradigm: a set of beliefs for understanding the world (Langdrige, 2007). Therefore, I will begin with the paradigm; then epistemology, phenomenology and their relevance to language and interpretation. This will ground my work before arriving at my chosen method of IPA.

#### **3.1 Paradigm**

The majority of research on SCA survivors with psychological and emotional distress has been underpinned by a positivist scientific paradigm. The scientific aim has been to increase knowledge by using objective measures, such as psychometric testing, to compare and contrast the degree of psychological dysfunction across people who have survived cardiac arrest. Unlike this approach, I aim to capture the subjective experiential account of being a SCA survivor: a detailed exploration of how a person narrates their story by putting it into their own words, feelings and concerns around the SCA and their lives. In this way, 'self-reporting' goes beyond grading elements of emotional well-being or distress via questionnaires to freer self-expression. Through increased reflection, a survivor may develop more awareness of their emotional health, allowing for greater clarity and knowledge of the experience to emerge, and to be passed on to others. For healthcare, this means that survivors' personal experiences, affective responses and outcomes capture detailed lived psychological realities.

My research assumptions and beliefs are embedded in an interpretivist paradigm. This means that all individual knowledge and personal experience constructed inter-subjectively is through socially developed meanings. My participants' subjective lived experience will always be a negotiation between their cultural, social and historical makeup. It is through this unique lens that individuals negotiate meanings based on how things appear to them in reality (Langdrige, 2007). My role as researcher will be vital in co-constructing with participants an interpretation of their lived

experience. This stance, unlike a positive paradigm, infers that the 'knower of experience' is inextricably linked to the experience itself. Therefore, it is only through a subjective, detailed and narrated exploration of the personal accounts of SCA that lived truths of the phenomenon will be negotiated. This subjective account aims at objective understanding.

### **3.2 Epistemology**

My position leans towards experiential epistemology, in which 'knowledge' means experience through a natural description and interpretation of phenomena, constructed through language and dialogue. How the world appears to an individual, their perception of it and how it is experienced will vary in its meaningfulness. The assumption here is that people will experience similar events in different ways; therefore, focusing on individual's perceptions and lived experience is necessary. This fits with my aim to capture experience through a descriptive rich and detailed account of how the world appears to people and what that means to them. How this examination of human experience takes place led me to phenomenology and its roots in continental philosophy.

### **3.3 Phenomenology**

Phenomenology is the study of human experience of how objects, or phenomena, appear to people in their consciousness. The philosopher Husserl (1931) founded it, in an attempt to move away from mainstream scientific enquiry, which he saw as 'seeking absolute truths', to one where there were different interpretations of experience. He believed that truth demonstrated itself through the verification of different perspectives using 'reductions', further detailed below. Consciousness is seen not so much as being intrapsychic (happening within a person), but rather outside that person in the space where it is directed towards an object. In this sense it is always 'being conscious of something', and how things are perceived will depend on how they appear to each person.

Husserl (1931) argued that, since phenomenology bases itself on the premise that all human experience derives from intentionality, therefore all human actions, intentions, thoughts, and feelings have an intended object. By looking at these intended objects one is able to show how consciousness makes sense of the world as it is encountered (Cooper, 1990). In order for meaning to be uncovered through experience, Husserl believed that one needs to get to the 'essence of



things' and 'by looking for essences behind direct appearances' (van Deurzen, 2013 p. 4). Husserl termed this 'eidetic reduction' in which the phenomenon is creatively broken down to its finite form to examine the structure and pure meaning of it. In order for this to happen, one would need to separate from what he termed a 'natural attitude', an assumptive everyday way of experiencing the world with little attempt at examining possibilities.

This requires 'bracketing' of what one already knows and assumes, in a process Husserl called 'phenomenological reduction'. The focus is on describing the experience, as opposed to analysing or interpreting what one observes. One therefore begins by paying equal attention to the importance of things, verifying observations and checking descriptions with a person or text. He believed that only by putting aside one's own biases is one able to transcend one's own experience and encompass multiple perspectives, which he called 'transcendental reduction' (Husserl, 1931).

Moving from a pure descriptive Husserlian phenomenology led me to enquire into existential phenomenology and hermeneutics. This included works from the philosophers Heidegger, Merleau-Ponty and Sartre. By focusing on questions of existence, Heidegger (1962) sought to contextualise phenomenology as well as show the intersubjective, relational and situated aspects of how people reflect their world. He believed that people were culturally bound and historically situated in a particular life frame and it is through this lens that one engages with life. He further states, 'what is a phenomenon can be concealed because phenomena, for the most part, are not given and phenomenology is needed...a pure letting is seen, but rather in its indicating always has recourse to something else' (p. 30). In other words, it is only through examination that the meaning of things may emerge. He therefore moved away from simply describing phenomena towards a hermeneutic phenomenology, which bases itself on interpretation.

Merleau-Ponty (1962) describes the individual's relationship to the world in terms of 'embodiment' and us as 'body subjects'. This implies that one experiences, perceives and interprets phenomena through the wholeness of being a 'body' rather than through its separate parts as an object. This, unlike Husserl's original phenomenology, incorporates the body as shaping what we know about the world. In this context, SCA survivors have embodied and reflected on their experience with or without personal reference to memory. The freedom of choice that follows allows individuals to place meaning on events, which influence the future (Sartre, 1943).

By exploring outlook and well-being in SCA survivors using a phenomenological perspective, I aim to show how people see their world, reflecting their position, history and intentionality (Van Deurzen, 2014). I propose that hermeneutic phenomenology will allow deeper meaning to be uncovered as participants engage with and interpret their world in relation to others. The emphasis is on the world as lived by a person, not the world or reality as something separate from the person (Laverty, 2003). This focus on how things have been perceived and experienced has led me to a phenomenological enquiry.

### **3.4 Language and Interpretation**

Language is important to phenomenology, as it is through language that one expresses thoughts, feelings, memories and experience (Langdridge, 2007) through a negotiation of words, grammar, and syntax. 'How one chooses to describe their situation constructs and shapes a particular version of their experience rather than it expressing reality' (Willig, 2008, p. 66). In an attempt to discover meaning, Schleiermacher (1998) argues that both writer and text need an understanding of both intentions and expressions, which are unique constructs.

Heidegger (1962) believed that individuals speak from a place dependent on the historical period and culture they live in, seeing individuals as determined and limited by our prejudgments. Gadamer (1975) termed the particular outlook or stance one has on life 'horizons' and argued that, although limiting, they are not fixed. What is necessary is a 'fusion of horizons' where one meets others and their viewpoints, eventually accommodating them and arriving at mutual understanding. One can view this fusion in my role as a researcher engaging with the text, bringing my own preunderstanding and way of seeing things together with that inherent in the text to reach mutual understanding. Gadamer further argued that our particular beliefs stem from our 'traditions', which have a set of biases, and therefore hermeneutics is needed to grasp the understanding and meaning of each participant.

Ricoeur (1975) supports Gadamer's ideas on a hermeneutics of meaning-making or empathy and seeking mutual understanding through a historical and cultural lens. He argues that 'every consciousness of meaning involves a moment of placing at a distance lived experience' (p. 97) to interpret and signify the experience. However, he goes further in his quest for meaning to include multiple hermeneutics and focuses on interpretation to include a 'hermeneutics of suspicion'. His

ideas stem from an assumption that one needs to confront text with an element of suspicious enquiry, to unravel that which remains hidden in order for meaning to arise (Langdridge, 2007).

He believed that a questioning, critical and empathic approach was vital (Ricoeur, 1975). This is useful to my study so long as the critical element and interpretation stay close to the meaning of the experience. However, this approach, often used in discourse analysis, uses theoretical perspectives from outside the text to explain social and psychological phenomena. In this case, it does not complement my study aims and has a different epistemological position than my proposed IPA.

In IPA, by using a hermeneutics of empathy, the approach attempts to reconstruct the phenomena in its own terms. This means that the relationship between researcher and text, and the different levels of interpretation, stay closed. It does not bring in an outside source or theory, particularly in the early stages (Smith, Flowers, & Larkin, 2009), which differs from Ricoeur's methodology. I have chosen IPA over discourse analysis because it supports my aims of staying close to the phenomena in uncovering meaning, which is co-constructed and directly linked with the data. My epistemological focus is experiential, focusing on how one creates knowledge and meaning through interpretations of lived experience. This differs from discourse analysis where knowledge becomes a social construction through language aiming to ground discourses in social and institutional practices (Willig, 2008).

### **3.5 Interpretive Phenomenological Analysis (IPA)**

IPA draws from wider phenomenology, using hermeneutics to achieve a more complex understanding of lived experience. At its core is the exploration of phenomena by an individual through their detailed account of lived experience. This is a subjective reflection on how one expresses what an event has been like and what it has meant, including unique perspectives and meanings, representing one's relationship with the world. How this experience between researcher and participant collects itself requires an open phenomenological attitude and carefully selected questions and criteria aimed at describing phenomena in detail. In addition, it is important to manage and maintain an awareness of researcher subjectivity or preconceptions. For example, it may be only during or after analysing text that one is aware of preconceptions or 'fore-structures' (Heidegger, 1962), allowing for more reflexivity. The aim is to apply objectivity when analysing

subjective accounts.

Therefore, the data collected is a co-construction between researcher and participant during the interview. My analysis will move from familiar aspects, such as similarities amongst participants, to what is unique, in a circular way, from the whole to the parts and back and forth (Gadamer, 1975). This is in order to understand the dialogue and gain the meaning of the text at different levels, which is also termed a 'hermeneutic circle' (Smith et al., 2009). Interpretation will be expressed as, 'not the acknowledgement of what has been understood, but rather the development of possibilities projected in understanding' (Heidegger, 1962, p. 149). In my analysis, I aim to interpret my participants' interpretations of their experience, in effect a double hermeneutics.

I have arrived at IPA as my chosen method since it has at its core a concern with how people make sense of major life experiences (Smith et al., 2009). For this reason, it is termed 'idiographic', in which people's approaches to experience can be received as detailed and deep analysis. I will also focus on the relational aspect of the experience, looking for similarities and differences in how these may diverge or converge across my participants. Using IPA, with its grounding in phenomenology, hermeneutics, and idiography, allows for the capture of these important elements of experience for a rich and detailed exploration.

### **3.6 Other Methods**

I have chosen not to use the 'grounded theory method' although it shares some similarities with IPA such as open-ended interview questioning, data analysis, and coding. This is because its research aims generally set out to generate a theoretical account of a social situation or process via sampling on a large scale. These 'macro' claims aim to produce theories grounded in the data (Smith et al., 2009). These are developed to study basic social processes, whereas IPA is a specifically psychological research method.

Grounded theory has its roots in a positivist epistemology, not accounting for researcher reflexivity (Willig, 2008). IPA as a method reflects my aim to capture individual, detailed and nuanced analyses of lived experience on a microscale, rather than with a large population sample. The researcher role is a crucial part of how my interviews, data, and knowledge are co-constructed. There are also different versions of grounded theory methodology bringing ambiguities into the

original theory.

I could combine them, but my aim is not to capture the lived experience of participants and then explain this in terms of wider social processes and their consequences. Rather, my aim is to explore how phenomena can affect an individual's psychological well-being, interactions and relationships with others. In other words, people who share an experience, and personal meaning- and sense-making in that context (Smith et al., 2009). There are clear and decisive steps in IPA, making it appealing for my research in terms of having a concise structure that can enhance validity.

The longest standing phenomenological methodology of Giorgi stays close to a descriptive Husserlian method revealing similarities in experience. Although idiographic analysis is used, its aim is to generalise the phenomenon regardless of the individuals concerned (Shinebourne, 2011). Therefore, idiography is not a key feature as it is in IPA, which is vital for my research topic. IPA draws on wider phenomenology and is interpretive as well as idiographic, enabling a more detailed and rich exploration of individual experience.

Van Manen's methodology, as with IPA, draws on phenomenology and hermeneutics. It is seen as an interpretive process in which the researcher makes an interpretation and 'mediates' between different meanings (1990, p. 26) of the lived experience. Although van Manen does not approach phenomenology with a set of rules or methods, he discusses phenomenological research as a dynamic interplay between a number of research activities. However, he grounds his work within a pedagogical research group focus, rather than psychology. Along with this difference in research focus, IPA also draws from 'symbolism interactionism', showing how meanings are constructed within an individual's social and personal world (Shinebourne, 2011). However, pedagogy draws from semiotics and the way elements of language (such as signs and symbols) come together.

I have chosen the method of IPA for the above-mentioned reasons and the confidence of having a clear, rigorous framework.

### **3.7 Validity**

#### **Limitations**

As with other methods, IPA has its limitations, one of which is the assumption that language will be a valid representation of one's experience. IPA relies on language to capture individual thoughts, feelings and memories (Willig, 2008), which may be difficult. Some people may not be able to articulate their feelings and hence would not be suitable participants. For my study, it was important to make clear to my participants that they needed to be comfortable reflecting on and talking about their experience in detail. I reiterated this through my conversations via email at the selection stage, pre-interview telephone call and information sheet.

In terms of being replicable, IPA does not ascribe to this concept, as this is a reflection on a particular experience recounted at a present moment between two people. Knowledge is not considered objective (in qualitative studies): it is shaped by the purpose and perspective of a study. Therefore, another researcher asking similar questions may collect different data. What is important, however, is that I have shown my steps (outlined below), illustrated with examples from evidenced appendices.

#### **Evaluations of Quality**

Different criteria have been proposed for assessing validity in qualitative studies, and like Smith et al. (2009) and Langdridge (2007), I will use Yardley's (2000) four principles for this assessment.

Yardley's first principle is that of sensitivity to context, which asks the researcher to have a good foundation in the methodology and epistemology underpinning the research and method of analysis. This includes the socio-cultural setting in which the study took place and the relationship between researcher and participants, including ethical considerations. To begin with, I chose IPA because of my sensitivity to individual stories and lived experience. IPA requires close engagement with the idiographic and the particular, and hence a small purposive sample is used, in which all participants shared the same lived experience. To make sure of this, criteria points for the study were clearly stated in the recruitment poster. I further confirmed suitability via email and a telephone call to each participant.

My socio-cultural awareness is very important to this study and is rooted in its epistemology. This is where the language used by my participants, their social interaction, culture, beliefs and values are central to their story and data collected. How they have responded, interpreted and made meaning from their SCA experience is a combination of these influences. My questions elicited an exploration of personal experience, which included their social influences, family relationships, values and belief systems, historical and economic influences. These factors created a setting in which participants spoke of their stories, illustrated in the findings under theme headings, with verbatim quotations from the transcripts.

The interview location was whichever environment (home, therapy room, Skype) felt more comfortable and safe to them. The information sheet outlined these options so they were able to decide early on in the recruitment process. I built a relationship with my participants by communicating with them throughout. This began with initial emails, the information sheet, telephone call and eventual interview. I kept the lines of communication open so they could ask any questions. I wanted to make sure they were comfortable speaking with me at length in an interview and build a rapport. Before the interview began, I asked how they were and how they felt about talking to me that day. I also reiterated they could stop the interview at any time. These ethical steps were taken in order for participants to feel at ease with the process.

It was also important to put my study into context and relevant literature helped to show what had been done, and compare it with new findings. This helped to link the work of others in the field with the current study and is illustrated in my discussion post-analysis.

The second principle refers to commitment and rigour, and emerges by engaging with the topic and data, through the process of selecting participants all the way to detailed meticulous analysis (Shinebourne, 2011). Supported by this research is my attentiveness to each participant during recruitment, at interview and analysis. After advertising via social media, my engagement with each participant began through email. I asked each person for a little more information on their story, making sure criteria were met and sending them an information sheet. I respected their decision to participate or not, as they had to feel comfortable talking about their experience. I built rapport by remaining attentive, following up in further emails and a telephone call before setting up an interview.

My grounding in phenomenology, hermeneutics and existential themes and staying close to the idiographic meant I was able to focus on each individual and their lived experience during the interview, and engage in their story. Whilst I remained attentive to their recollections, I asked some questions to further explore and expand on their experience. I was aware of emotional sensitivity to their personal stories and hence engaged gently, allowing them freedom to discuss their experience. This led to rich, detailed interviews (see Appendix J).

I also noted the tone of language, expressions and body gestures in order to support any difficulties. An example of attunement is my awareness of slight difficulties on two occasions where I asked participants if they wanted me to stop the interview. They appeared distressed while reflecting on their story. My training in psychotherapy and psychology of course, further supports this.

A commitment to each person's story continued where each interview underwent in-depth analysis. I immersed myself in the analysis, aiming to make sense of participants' sense-making. I aimed to show individual voices and group similarities in my findings. For example, idiographic engagement meant that if part of a sub-theme seemed important, even if it was not shared by the majority, I included it. This was the case with 'suicide as a possibility', which affected only two participants and is shown under the sub-theme 'Sharper awareness of own Mortality'.

Yardley's third principle relates to transparency and coherence of methods and data. I attempted to show methodological rigour and transparency by detailing each stage of the process. This included how themes were identified and integrated into meaningful clusters, first within and then across cases. The initial data coding of individual transcripts into descriptive, linguistic and conceptual workings through to emerging themes, superordinate themes and group themes has been consistent with the underlying principles of IPA (detailed in Smith's IPA, 2005). This is outlined in the methods chapter below, with reference to examples shown in Appendices.

I also attempted to show a considerable number of participant transcripts in my analysis to illustrate my themes. This allows the reader to check the validity of my interpretation, which is clearly but one interpretation, rather than a general claim.

It has been important as a researcher to add my own influences, assumptions and intentions,



which led to this study, as illustrated in the introduction and followed by my reflexivity section. My personal interest in family bereavement, personal loss, surviving death, training and clinical work in this field contributed to my desire to explore (and interpretation of) this topic from an emotional well-being standpoint and add to existing studies.

Coherence does not refer to having coherent results. Rather, as Smith et al. (2009, p.182) explain, 'it is not that contradictions shouldn't be in the data, they are often the richest part of the text, but the analysis of the contradictions should not in itself be contradictory'. In this study, some participants did not recount shock upon finding out they had experienced a SCA and been resuscitated, although there was still a sense of disbelief. This, therefore, became relevant to the general sub-theme of 'un-realness of event'.

Yardley's fourth principle is that of impact and importance. I hope that my research brings interesting results, adds to existing knowledge and that it could have an impact on how we view the world. SCA is an important phenomenon affecting a number of people who may need both physical and emotional support to recover from a potentially life-changing experience. As SCAs could alter how people live and view their lives in many different ways, it has relevance to individual support and the family unit. With increased awareness from clinical studies, particularly survivor experiences, the aim is to improve emotional support for those who need it and are struggling on their own.

The sensitive nature of this study means that, in giving a voice to those suffering in silence, they and others may feel less isolated and more integrated in returning to life and society. For health professionals, an added appreciation of SCA survivors and their unique experience might include the need for emotional support at varying stages of recovery. This includes an awareness of support for the community around those impacted by SCA.

In addition to these four criteria, Smith et al. (2009, p. 183) discuss the 'independent audit' as a crucial component of research validity. They make it clear that it is not about a different researcher being able to arrive at the same result (given the subjective nature of the research) but rather that the results are credible and make sense. This dissertation includes a table showing the interaction of themes, superordinate and subthemes, and each participant's contribution to each theme. This allows the reader to match these with the results, discussion and conclusion.

## 4 METHOD

### 4.1 Design

This study used semi-structured interviews with open-ended questions to focus on the quality of each participant's experience of surviving SCA. As this study is concerned with personal outlook and emotional well-being, the questions focused on exploring beliefs, feelings, and values. Questions 1-2 (see Appendix G) stay close to experience in terms of an account that is descriptive, explorative and considers what that was like for them. Questions 3-6 cover emotional well-being and how it relates to their physical, social, personal and spiritual health. Questions 7-8 look at how they foresee their outlook and future. The sampling is purposive, and a small and homogenous group selected.

### 4.2 Participants

There were 10 participants in this study. All lived in the UK; nine were British and the other American. Seven had their SCA at home; one at work; one on a sports field; and one in a swimming pool. All had their SCA witnessed by a family member, colleague, peer or bystander and were given CPR before emergency services arrived. They consisted of six males and four females aged between 31 and 60, with a median age of 45 years. The age at SCA was between 17 and 57 years, with a median SCA age of 38. The post-arrest time is between 2 and 20 years with a median post-arrest time of 9.

Participant	Gender	Age at interview	Age at SCA
1	Male	42	33
2	Male	51	49
3	Female	48	44
4	Male	60	40
5	Female	60	53
6	Male	39	34
7	Male	44	36
8	Male	59	57
9	Female	31	28
10	Female	37	17

Firstly, being a survivor of SCA is uncommon and was the first criterion for participating in this study. The second was individuals who experienced SCA without prior knowledge of a heart condition or pre-morbidity, as I wanted to explore survivors' experience from the perspective of otherwise healthy individuals who experienced SCA without a known cause. The third criterion was age; my sample group was currently aged between 30 and 60 as those older than 60 are likelier to have morbidity. Fourthly, a post-arrest time of at least 2 years was chosen in order to allow a substantial period to have lapsed, in which they would have reflected in detail and gone on an emotional journey, which could then be captured.

There is great variation in age and post-arrest time in my sample, which is inevitable when exploring this unique phenomenon qualitatively, in a non-hospital context without statistical reference. In addition, the focus of this research is on how individuals 'experience' their lives after SCA, rather than minimising all variables, for a purposive and homogenous sample.

## **Interviews**

Six interviews were conducted face-to-face: four took place in the home of the participant, one in a park and one at the Waterloo therapy room. The other four were conducted online via video-Skype. The interviews took place over a year from July 2014 to July 2015. I recruited individuals by means of a poster advertisement (see Appendix F) placed in online support groups and social media. The names of the groups remain withheld for reasons of anonymity. Participants who expressed interest in taking part contacted me initially via email, forum or website in response to my request. Interviews lasted between 1 and 1.5 hours, and were digitally recorded.

### **4.3 Method of Data Analysis**

For each interview, I listened to the recording and transcribed the interview. I read it once and then listened to the recording again, correcting any words that were missed and noting particular expressions and emotive cues. I reread the transcript. I then used wide margins on both sides of the transcript. On the left-hand side, I divided it into three sections: firstly, descriptive comments in blue, which were mainly paraphrasing what was there and noticing what was important to the participant. Secondly, in red I noted the particular grammar used, syntax, repetition of words, analogies and emotive expressions. Thirdly, in green, I made conceptual comments on the data,

which went deeper than mere descriptions and were more interpretive and enquiring (Smith et al., 2009). Text that seemed important, repeated words and amplifications were underlined (see Appendix H).

The next step was the development of emerging themes. I used the right-hand column to note these by looking at previous notes and exploratory comments and linking overarching themes that seemed evident. These reflected my own meanings and interpretations, which compared and linked to the data and participants' meanings. The themes were psychological abstracts, based on particular phrases used in the text as well as the overall meaning of the transcript. This illustrates the 'hermeneutic circle where the part is interpreted in relation to the whole' (Smith, 2010, p. 92).

To get a sense of connections between themes, I wrote them on pieces of paper and shuffled them (see Appendix I). I then organised them into superordinate and subthemes by identifying patterns. I either used a theme I already had or created a new one to use as a cluster or superordinate theme. There were some themes which were in opposition, and some clustered together. Some emergent themes were considered more important if they arose frequently and were supported in the text. Superordinate themes with their corresponding emerging themes were positioned underneath one another on paper in order to visualise each category. Some were removed, or changed around if they seemed repetitive, or a different expression supported them better.

I then created five to seven superordinate themes for each participant and three to seven subthemes under each of those (see Appendix J). Some further modifications occurred as I began to go through each transcript line by line and use examples from the transcript to support my themes. Some were removed at this point, where similar words existed.

A thematic table (see Appendix K) was created for each participant, with superordinate and subthemes. I went through each theme again, connecting it with extracts in the transcript by re-reading it line by line and looking at my earlier comments, underlining, and notes. I created a table listing each cluster, emerging themes, examples of extracts from the transcript and their page and line numbers. During this time, I further refined my clusters and combined some that had similar meanings, removing a few which were not concise. I used the same steps for each participant.

I ended up with 10 tables, which I placed side by side. Firstly, I looked at how the themes corresponded across participants. I then made another list, merging all the themes together. In all there were 64 superordinate themes and 236 subordinate themes, totalling 300 themes (see Appendix L). I could then see how often themes were repeated, the different wording used with similar meaning and those which appeared important. I then began to cluster themes into groups, superordinate and subthemes (see Appendix M). Some were easier to identify, as it was obvious they were recurrent themes amongst participants. This was usually evident in four or more interviews. When a theme was obvious in at least four participants, then it became a recurrent group theme. IPA being idiographic, I wanted also to show some uniqueness in participant themes and chose some expressed by only a few participants if I felt they were important.

I chose three superordinate group themes and 11 group subthemes; under each subtheme, further divisions were made to separate each point. I then used excerpts from each transcript table to show the relevance of group themes. I referred back to original transcripts to double-check the meaning of expressions and the context, to refresh my memory and make sure examples reflected themes. I then began my analysis by creating a visual diagram of themes, commenting on their relevance to participants' stories using examples from the text (see Appendix N).

#### **4.4 Ethical Considerations**

This research involves participants reflecting on their cardiac arrest experience and their lives. This can be an emotive and sensitive subject and therefore carries an increased risk to the well-being of participants and researcher. The personal and sometimes difficult nature of disclosing thoughts and feelings around illness, death, loss and trauma have potential to harm and make participants feel vulnerable (Liamputtong, 2007). With this in mind, I took a number of steps to reduce the risk of harm to participants. These included obtaining informed consent, discussing what to expect, clarifying confidentiality and de-briefing after the interview. I will also discuss steps taken to reduce risk to the researcher (see below). To begin with, I will describe how I sought ethical approval.

##### **Obtaining ethical approval**

I requested ethical approval via an Ethics Approval Form (Appendix A). The form asked if any

deception would be involved, where I would be recruiting participants and issues of consent. A number of forms attached to this application included a Project Proposal, which outlined a brief description of the nature and purpose of this study. This included details of the procedure: interview length, data collection, and the storage and reporting of data.

A completed Consent Form was attached (Appendix D) which explained participants' right to withdraw from the study at any time without penalty. A detailed Participant Information Sheet followed (Appendix C), which contained details of this study, and what to expect, including issues of confidentiality and anonymity in data collection, as well as researcher and supervisor contact details. A De-Briefing Form (Appendix E) was also completed and attached, which gave participants contact information of various counselling and support organisations if needed. Lastly, a Work Risk Assessment Form (Appendix B) was included, which detailed my travel arrangements to attend interviews, notification of next of kin and the pre-screening telephone conversation before the interview for risk assessment. After supervisor approval, all forms were submitted to the New School of Psychology and Counselling at Middlesex University, Department of Psychology. I received confirmation of ethical clearance on 22 November 2013.

## **Recruitment of Participants**

After advertising in online support groups and social media, interested participants emailed me if they wanted to be part of this study. I thanked each person for their interest and willingness to speak about their SCA. Where they stipulated 'they did not fit all criteria but would have liked to help', I explained the boundaries of the study. For example, if they had a pre-existing heart condition I would explain that, regretfully, I was not in a position to interview them for this particular study. Although the poster advertisement clearly listed all criteria had to be met, I asked for confirmation from everyone that contacted me. I also asked for a brief description of what happened to them on the day of their SCA. This included verification of current ages, when and where they had their SCA, any prior knowledge of an existing heart condition and where they were resuscitated.

## **Screening participants**

There were 34 individuals excluded from this study, as they did not comply with all criteria. These

people did not match criteria in either age (30 to 60), a minimum of 2 years post-arrest and/or no existing heart condition. I reiterated via email my gratitude for their time. I explained that I needed to keep within the ethical boundaries of these criteria as listed. I felt privileged to be given time with participants, entering their world and personal experience and sharing what was important to them in life. This made it difficult and upsetting to turn down participants who wanted to share their story and be part of this study.

There were individuals from other countries, which I had to exclude because of geographic location. There were 27 in the US, one in New Zealand, two in Australia, one in India and one in Belgium. I thanked them all for contacting me and was appreciative of their willingness to participate. I apologised, explaining to all that I did not have ethical approval to interview participants outside of the UK. As many were from the US, initially I sought approval to interview them via Skype through the Middlesex Ethics Committee. However, I did not gain approval since Skype is not HIPAA (Health Insurance Portability and Accountability Act) compliant and therefore inappropriate to use with US participants.

## **Obtaining informed consent**

When I had email confirmation that individuals fitted all criteria, I then explained I would be emailing them an Information Sheet, which they needed to read. The Information Sheet detailed the purpose of the study and gave more information as to what would happen if they took part. This included a preparedness to reflect on their thoughts and feelings (emotions) on their SCA, via an interview. It mentioned that interviews would be digitally recorded, transferred onto a USB stick and stored safely in a locked filing cabinet (Data Protection Act 1998). Their personal details were kept confidential with no identifying features linked to interview transcripts and published material (BPS Code of Ethics, 2009).

The Information Sheet also mentioned the possible benefits of taking part for survivors' reflection on their experience, as well as possible disadvantages in terms of invoking distress. If this were to happen during the interview, the form advised them to let me know and I would pause or stop the interview. It was also outlined in the recruitment paperwork that the study was a self-funded research project, with approval from the NSPC Ethics Committee (Appendix A) and they would have access to any publications arising from the study.

After a few days, I emailed individuals to see if they had read the Information Sheet and if they were still happy to participate. At this stage, eight people withdrew from the study and did not respond to further emails from me. This was difficult and frustrating at times in terms of not knowing what their intention now was. I assumed their non-communication was in effect a notification of them changing their minds and now not wanting to participate (and perhaps not wanting to confront that decision). Fourteen people agreed via email to participate in the study and a brief telephone conversation was arranged with each. They were able to choose a time that suited them as I anticipated some might prefer to be alone, or at home whilst having our conversation.

Our telephone conversation was to further clarify how comfortable and willing they were to talk about their SCA and be part of this study. I also pointed out that it was on emotional well-being and that some questions would be on their feelings and thoughts throughout this experience. This enabled them to ask me any further questions in order for us both to have transparency (i.e. a clear idea of requirements and comfort or assurance that one knows what one has agreed to). It was also an important opportunity after a series of emails to connect further by speaking over the phone.

I found it helpful to speak with each person, giving me a sense of who they were as individuals. This included how they felt about speaking to me about their SCA and whether they had spoken much about it before. This gave me some insight into how easy or difficult this may be for them, including how important it was for them to share their story. I felt this helped build a rapport and they were free to contact me at any stage. This ideally gave a small indication of what it would be like talking with me for an hour in an interview. I also made some brief notes after the call, including my own personal reflections and feelings about our conversation. At this point one person withdrew from the study, explaining they would be too shy to talk at length about their experience.

I then emailed participants to arrange a convenient location (somewhere they felt safe and comfortable, and quiet to minimise disturbance and maximise confidentiality), date and time for the interview. At this stage, three people withdrew. Two people replied via email stating they had not spoken about their SCA before and were hesitant to do so now. It was challenging and upsetting to hear this, particularly so close to interviewing, as it had been difficult recruiting



people. Nevertheless, I reassured them that their decision was fine, as they had to be comfortable with reflection.

The other person did not respond to further emails from me. Again, it was difficult to know their intention and I could only assume they had decided to withdraw through, perhaps, fear of confronting thoughts and feelings. Our conversation may have highlighted how unprepared or uncomfortable they were speaking at length. I experienced feelings of sadness and disappointment, mainly because I had spoken with the person and built rapport, sensing they would advise me if they had changed their minds. However, I understood that having that conversation might not be easy if perhaps one person felt they were letting the other down.

After interview dates and times were agreed, I then emailed each participant a Consent Form. I asked them to read, sign and return (via email) to me before the interview. When conducting interviews in person, I took a hard copy of the consent form with me, stating they could sign it beforehand on the day. On the day of the interview, I reiterated before taping commenced that I would be protecting their anonymity and no names or identifying organisations would be linked to them for the purposes of confidentiality. If they for any reason wanted the interview stopped at any time, they were free to let me know.

## **Conducting the interviews ethically**

Given participants may feel particularly vulnerable disclosing emotive experiences, it was important I helped build trust and a safe environment. This was paramount throughout the process and given many years of counselling adults, not least in bereavement and loss, I was aware of my responsibilities to minimise harm. Arguably, in health and social care, being motivated to promote a sense of care, respect and trustworthiness are of utmost importance, including developing meaningful relationships and responding to distress (Banks & Gallagher, 2009). I therefore began by asking participants how they felt on the day about speaking with me on the subject of their SCA. I mentioned they could take their time and disclose what they felt comfortable with during the interview. I felt this gave an opportunity to build our relationship with one another and relax before commencing the interview. It was important for me to create a safe space with a warm presence so participants could feel comfortable talking about their emotional experience.

The interview process involved questions, but also space and freedom for them to comfortably express themselves and explore their experience. I respected their right to describe how the experience was for them in their own terms. The value was in their own self-expression, which is open and free for their own exploration, rather than too formulated. It is also important participants felt at ease engaging in conversation naturally at their own pace, in order to allow more open and honest dialogue with greater richness (Langdridge, 2007). If they ventured off the topic, then I would slowly bring them back to the focus of the question. This is important also to the quality of the data collected and enabled a joint exploration of the person's worldview about the topic (*ibid.*, 2007).

Two participants began crying during the interviews and appeared distressed when recounting parts of their SCA experience. I immediately attended to them, providing containment and safeguarding. I did this by stopping the tape and gently asking if they were okay. I provided tissues and advised they should take their time and that it was totally fine to not continue if they so wished. They both quite quickly decided they wanted to continue with their story. I asked if they wanted more time and that they were sure they wanted to continue. I then respected their autonomous decision to continue with the interview, and taping recommenced. This obviously had an impact on me in that I could see how upset they were, and I felt sad and moved by their emotional journey. It was heartfelt, invoking empathy and a sense of wanting to protect them. I also felt a responsibility in my duty of care to lessen harm during these interviews and in my researcher role.

## **Debriefing**

After each interview, I gave a debriefing. I asked each person how they found the experience, where they could further reflect and take an 'emotive' step back from their SCA story. They were able to discuss any thoughts, feelings or concerns. After the interview, I handed (or emailed) each participant a paper or electronic copy of a detailed contact list, containing support and counselling organisations and supervisor details. Contact information for my supervisor and me was provided on the form, allowing participants to discuss their involvement further if they so wished. I thanked each person for their contribution, reminding them they could contact me further if needed.

## **Minimising risk to the researcher**

Avenues of self-care have been part of my clinical training in psychotherapy and counselling psychology since 2010. As this emotive topic of SCA has some personal relevance, it is important to mention the possible risk of harm to the researcher. I minimised this risk to myself by keeping a reflective diary and being in personal therapy, as well as having academic supervision throughout. This provided an outlet for my own expression, keeping me safe and grounded. Nonetheless, I found it upsetting at times hearing the emotional turmoil recounted by my participants. In particular, their feelings of loss and fear of death I found emotive and heartfelt – there was a sense of connecting with the deepest of human issues. This made me also think about my own life, death and feelings of loss in general terms, and in particular, the felt-sense of loss from an early stage growing up within my family unit. We ourselves become vulnerable in the face of others' distress (Liamputtong, 2007), and this is different from emotional distress.

However, not having personally experienced SCA nor having a memory of one in my family, my own experience is one of others' recall rather than 'living through'. This provides distance in terms of minimising the chance of researcher and participant conflation. Using my counselling skills, I found it easy to sit with and be calm and supportive whilst empathic to their stories. I was surprised by the level of emotion expressed at various points in their recall: in particular, feelings of suicide after their SCA. It was sad, difficult and contradictory to hear (after surviving death) how desperate and isolated some participants had felt at the time. Although I had speculated about this, I was also surprised how many individuals felt they had become better people after their SCA. There was more attunement to their positive qualities, needs and the importance of values.

In terms of practical ethical issues, a Work Risk Assessment Form (as previously mentioned), was completed and submitted to the ethics committee. This is in keeping with 'health and safety' and ethical considerations for research occurring outside of the academic institution. As six interviews took place in the homes of participants, I notified my next of kin with my contact details (mobile number and town/city I was going to) before and after each interview. I therefore carried a mobile 'phone and organised interviews during daytime hours, usually a morning. Four interviews were conducted via video Skype. Having the option to video Skype as well as an interview in person gave those who were not able to meet face-to-face due to geographical or situational constraints the ability to participate. On reflection, it may have also made a sensitive topic easier to talk about

online where there is an element of distance: a screen between participant and researcher.

Although using video Skype still allows one to listen, see the other person and observe gestures and non-verbal behaviour, there were differences between Skype interviews and those conducted face-to-face. I found it easier to relate to the person when we were face-to-face in person, and having that presence there, without the screen between us. I felt I could get a better sense of their emotive experience and realness with body language (although, while staying attuned to this, I focused on attending to what my participants said and how they said it). For example, if any distress was evoked, I would have managed this on Skype by stopping the tape and attending to them (in the same way as I would face-to-face). I would have said it was fine to stop the interview if they preferred.

When online, I was also concerned that the technology (the internet and recording) might fail. Therefore, I said to each person in the interview that if our connection was lost (and upon re-trying, failed again), I apologise and would be in touch immediately via email or telephone. I was aware of these potentialities and others (for instance, if my train had broken down on the way to a face-to-face interview). I felt that by keeping lines of communication open (i.e. having email and a telephone number), I would be able to contact them by various means in the unlikely event of accidental changes. In the event, the interviews were carried out without incident.

I found that ethical conduct remained fluid throughout the research process. I was aware of it being a sensitive topic and aimed to be transparent throughout. This included being clear on what I was doing, why and what it involved. While recruiting, I found more and more people contacted me to say how important this topic was and that more research was necessary. The potential findings that could benefit the group seemed to outweigh potential concerns and gave some justification in terms of a moral obligation (Liamputtong, 2007). Accessing vulnerable groups can be also difficult and this has certainly been the case in this study. It was also found to be important for every participant (and many others who expressed interest but did not fit the criteria) to have their voice and story heard. Predominantly, this was to enhance the care received during and after SCA and make society more aware of survivors' needs. Many felt there was a distinct lack in the emotional and psychological aftercare of SCA survivors. In this context, qualitative research poignantly allows them to tell their story, empowering their sense of well-being.

## 4.5 Reflexivity

My initial assumption was that I would be collecting information via questions I had developed to explore participants' experiences on physical, social, personal and spiritual levels. These questions were useful in directing me along this path and I could refer back to them whenever the conversation stalled and it was time to move on to a different area, so in that sense they were my guide. I found as I progressed through interviews I could refer less to a formal format and incorporate questions as was fitting to the conversation, rather than in a specific order. I feel it was important to get a sense of lived experience, going beyond what a series of clinical questions and answers may capture. What I found was a rich story within every participant, in which they all freely expressed their thoughts and elaborated on their experiences.

At times, with some participants, this led to exploring other areas linked to their experience, so we would go back and forth between questioning and elaborating and allowing them to speak freely. I directed the interviews in a certain way, with questions around outlook and emotional well-being, incorporating the four dimensions mentioned. Therefore, the expressions of their story and how participants constructed meanings shaped the findings, and is a co-creation with my role as researcher.

My assumption was that outlook changes after having experienced SCA. Since individuals change throughout life, an event like SCA will presumably change the world as they see it, altering their sense of reality and the need to incorporate this new experience. This meant that at times I directed the focus of the interview towards the emotional impact of SCA and prioritised this over other aspects in order to unpack emotional well-being. However, upon reflection, one can capture emotional well-being when describing other elements of their experience. I managed this progressively by allowing questions to flow without a particular order, but rather specific to each conversation. Keeping a personal diary after each interview meant that I was able to reflect with some distance. Attending personal therapy further supported my reflective experience and I was able to connect with my own thoughts and feelings after each interview and throughout this research. I also transcribed each interview as I went along, which allowed me to further reflect on my role as researcher/interviewer.

My own personal values and indirect experience of SCA fed my continual interest in unfolding the

lived experience of SCA, which included what it had meant for participants. This study has helped shape my learning about SCA in all its complexities. It has enabled me to gain insight into the emotional lives of those who survive years later and the struggles that can ensue after it. It has made me more aware of this phenomenon affecting younger people suddenly and the effects it can have on their lives. Equally, it has shown me that this phenomenon is unique, particularly when experienced suddenly without morbidity. Therefore, there is a need for increased emotional and mental health support for those who struggle with the repercussions of their SCA. Survivors often feel alone, confused and not properly understood or validated. Not least, it has been meaningful for me to give voice to these individuals, and I hope that health professionals will gain greater awareness of the potential suffering caused by SCA.

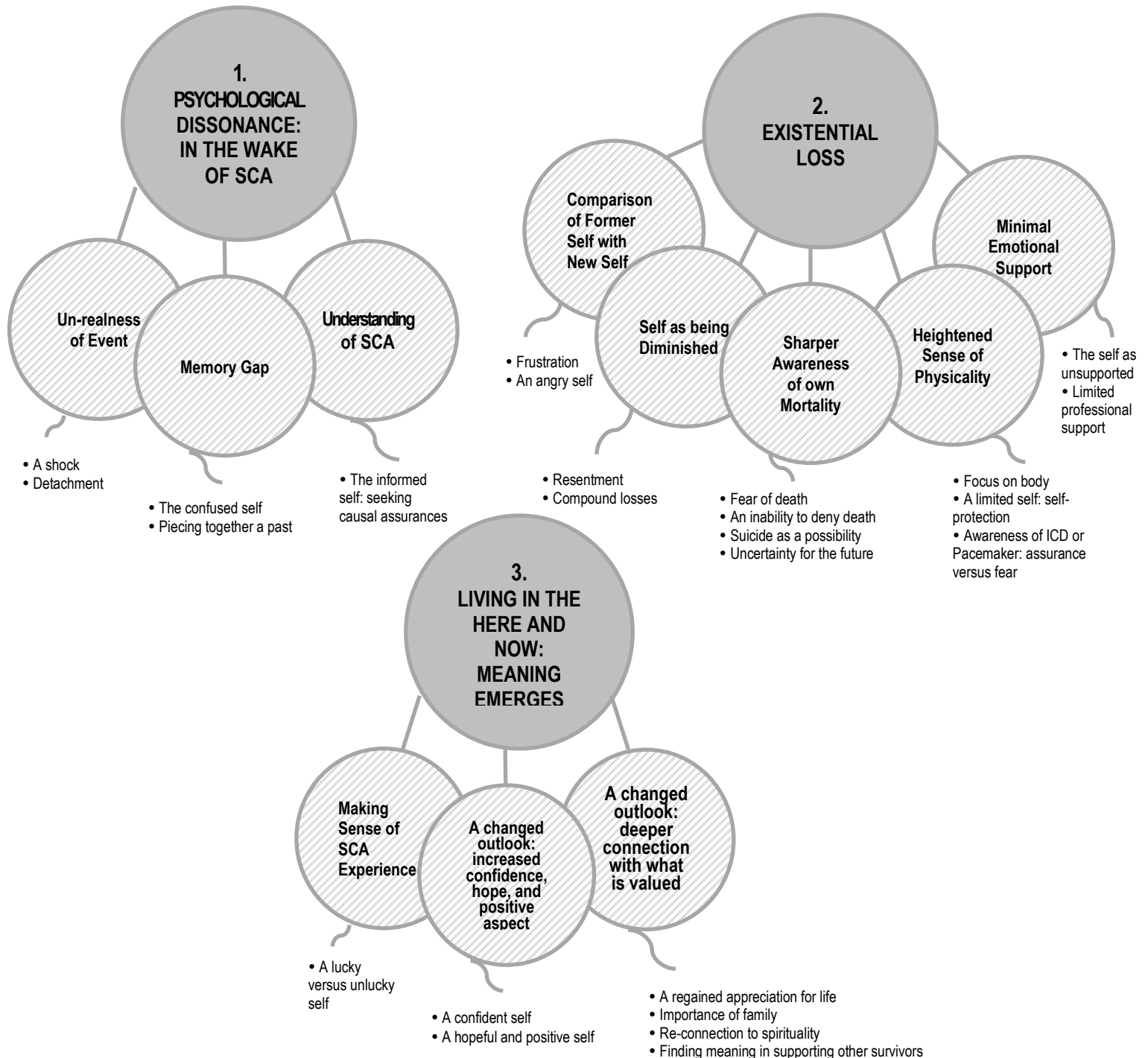
## 5 RESULTS

Three superordinate themes emerged. These are illustrated below with connecting sub-themes.

*Theme One: Psychological Dissonance: In the Wake of SCA*

*Theme Two: Existential Loss*

*Theme Three: Living in the Here and Now: Meaning Emerges*



I will commence with a detailed look at participants' descriptions of their experience of psychological dissonance in the wake of SCA, which is the first superordinate theme. This is in the hospital setting in which medical staff or family first inform them of their ordeal. I will then move on to the second superordinate theme, which is the experience of existential loss while in recovery and continual post-recovery. This will be considered in terms of what SCA represented to participants, particularly in terms of loss and how they viewed themselves. I then will turn to their descriptions of the experience of living in the here and now, which is the third superordinate theme. This will be an in-depth look into what meaning they made of their experience.

Firstly, as this is a qualitative study, it is important to show the interaction of themes and how often these ideas are expressed by participants, rather than in statistical numerical form.

Fig A. A master table of themes, with transcript line numbers corresponding to each theme.

Fig B. A further table shows a quick reference to identifying recurrent themes present in the sample.

These are discussed further in the pages that follow in this section.

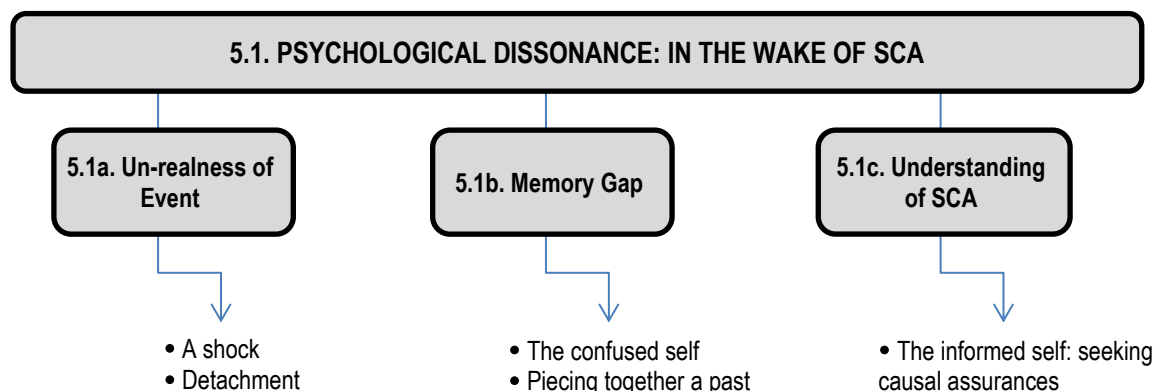


*Fig A*

SUPERORDINATE THEME ONE PSYCHOLOGICAL DISSONANCE: IN THE WAKE OF SCA										
Participant Transcript Lines P1-P10:										
Subthemes	P1 (Dave)	P2 (Norman)	P3 (Diane)	P4 (Nick)	P5 (Teresa)	P6 (Bill)	P7 (Harry)	P8 (Steve)	P9 (Wendy)	P10 (Linda)
1A. Un-reality of Event	125	285	409, 643		109, 422, 507, 552		36, 77, 116		56	
1B. Memory Gap		109	628	26, 142		96, 157		118	79	120
1C. Understanding of SCA	63		317, 630	55	128, 1186, 1198	686, 799	91			
SUPERORDINATE THEME TWO EXISTENTIAL LOSS										
2A. Comparison of Former Self with New Self	403	339	729, 894		1115		389	499		1178
2B. Self as being Diminished	465	577	495, 563, 818	170	914, 1338		145	171		200
2C. Sharper Awareness of own Mortality	380	190	512		215	863	588	189, 736	1371	
2D. Heightened Sense of Physicality			524	962	746, 1147		267, 464		660	722
2E. Minimal Emotional Support			363	228, 757	998	441		611	1053	263
SUPERORDINATE THEME THREE LIVING IN THE HERE AND NOW: MEANING EMERGES										
3A. Making Sense of SCA Experience	181, 430		873			271	620	836	1243	
3B. A Changed Outlook: increased confidence, hope, and positive aspect				607, 979	878, 1081, 1436	511, 519	443	714, 871	1293	1109
3C. A Changed Outlook: deeper connection with what is valued	367		695	241, 516, 679	828, 954, 1051, 1332	536	167, 504	883, 1064	755, 1149	255, 629, 1010

*Fig B*

SUPERORDINATE THEME ONE PSYCHOLOGICAL DISSONANCE: IN THE WAKE OF SCA											
IDENTIFYING RECURRENT THEMES											
Subthemes	Dave	Norman	Diane	Nick	Teresa	Bill	Harry	Steve	Wendy	Linda	Present in over half of sample?
1A. Un-reality of Event	YES	YES	YES	NO	YES	NO	YES	NO	YES	NO	YES
1B. Memory Gap	NO	YES	YES	YES	NO	YES	NO	YES	YES	YES	YES
1C. Understanding of SCA	YES	NO	YES	YES	YES	YES	YES	NO	NO	NO	YES
SUPERORDINATE THEME TWO EXISTENTIAL LOSS											
2A. Comparison of Former Self with New Self	YES	YES	YES	NO	YES	NO	YES	YES	NO	YES	YES
2B. Self as being Diminished	YES	YES	YES	YES	YES	NO	YES	YES	NO	YES	YES
2C. Sharper Awareness of own Mortality	YES	YES	YES	NO	YES	YES	YES	YES	YES	NO	YES
2D. Heightened Sense of Physicality	NO	NO	YES	YES	YES	NO	YES	NO	YES	YES	YES
2E. Minimal Emotional Support	NO	NO	YES	YES	YES	YES	NO	YES	YES	YES	YES
SUPERORDINATE THEME THREE LIVING IN THE HERE AND NOW: MEANING EMERGES											
3A. Making Sense of SCA Experience	YES	NO	YES	NO	NO	YES	YES	YES	YES	NO	YES
3B. A Changed Outlook: increased confidence, hope, and positive aspect	NO	NO	NO	YES	YES	YES	YES	YES	YES	YES	YES
3C. A Changed Outlook: deeper connection with what is valued	YES	NO	YES	YES	YES	YES	YES	YES	YES	YES	YES



## 5.1 Psychological Dissonance: in the wake of SCA

This was an overarching theme in which participants commented on their experience of awakening in hospital to the unexpected and sudden news that they had had a SCA. Most participants had no memory leading up to the event and for some, this extended to days, weeks and months. Some had fragments of memory linked to multiple arrests in hospital. Survivors now faced a new reality. Their responses include reflections highlighted by the following subthemes: The ‘*Un-realness of the Event*’, which included a sense of shock and detachment, represented by six participants. The ‘*Memory Gap*’ was described by seven participants who had no memory of the event (up to months before). They spoke of confused feelings and a need to piece together information of events from loved ones in order to gain recollection of what happened to them.

Often there is confusion as to which fragments of memory are remembered and a sense of disorientation at having to create a timeframe that otherwise seems unreal. A few participants felt it was a positive thing not to have a memory of the event and construed it as a protective element whereby the brain shielded them from the traumatic experience. An ‘*Understanding of SCA*’ is represented in six participants, who felt a need to further understand and grasp the implications of their SCA, in terms of furthering their knowledge and seeking causal explanations.

### 5.1a. Un-realness of Event

Waking up in the hospital to the sudden news of their cardiac arrest, most participants recalled being shocked. They could not believe or understand what had happened to them. The

suddenness made it seem unfathomable: that life could be gone in an instant. *“It sort of hits then, like, you know, that something has happened. Something life-changing has happened to you, but you’re still here, um, which was just a big shock”* (Harry: 77). Harry was shocked to find himself in a serious predicament in hospital after making efforts to keep fit by playing sport and exercising. It was particularly odd for him to hear he had gone into cardiac arrest whilst on the football field and initially in hospital assumed otherwise. It was familiar and made more sense to him initially to assume he had injured himself by tackling another player: *“I thought I must have banged heads with somebody and that’s why I must have been knocked out. I thought that it must have been that; it couldn’t have been anything else, because I was probably the fittest person in our football team”* (Harry: 36).

A sense of surprise at his body failing him created a contradiction: a separation between the body and SCA event itself. This is where he questioned SCA having ‘chosen’ him randomly, as opposed to part of his body failing him. This challenged his earlier beliefs and efforts at maintaining a healthy and fit body. In this context, some preconceptions he had held throughout life, as well as his outlook, appear challenged.

*I’ve always looked after myself, sort of like health-wise and sport-wise, healthy and doing that, and [I] still do that. Um, so why did it pick on me to happen, you know? Yes, it was amazing that I survived this, but it was like, sort of, ‘why did it happen in the first place?’ Because from that moment in time, it totally changes; well, it could totally change your life* (Harry: 116).

Norman had no memory of the day of his SCA or the weeks leading up to it. He was outside fixing his car when his neighbour saw him collapse, called the emergency services and started resuscitation. In the hospital, his neighbour informed him what had happened. He found the news difficult to comprehend in terms of how much he had gone through. The experience of shock at his neighbour’s recall meant he needed to hear it repeatedly, as though he could not fathom what he himself was not privy to, and in a sense, could not internalise. *“It was a bit shocking. Um, my neighbour came around and sat and told me basically what he done and that....I just couldn’t take it in...he told me two or three times”* (Norman: 285).

Teresa too expressed her disbelief at not being able to take in how strikingly odd the event was for her: *“I was just in very much a weird sort of shock, I suppose. I mean, I wasn’t...it just took me a long time to come around to the thoughts of what had happened really”* (Teresa: 422). She found the enormity of

surviving a SCA a constant reminder, years later. Understanding what had happened and trying to make sense of it became difficult from the onset, where no clear-cut explanations existed. *“How do you take it in? It’s something so dramatic happened to you and nobody knows why really, why it’s happened”* (Teresa: 109).

Diane experienced a lot of fear after her arrests in the hospital and prepared her family in case she did not survive another. The suddenness of it happening once and then twice more in hospital created a frightening and disorientating sense of disempowerment. This fear constantly revisited her since her SCA. The shock at having to have this conversation at her age made her upset and angry as she recalled the events. The meaning she made from it is in terms of the fear and uncertainty she experienced, both at the time of her arrests and afterwards.

*On the third one, I kind of experienced a small part of that cardiac arrest where previously I hadn’t and it was then that it sunk in: ‘gosh, this could go really, really wrong’ and then I had that conversation which was quite awful really, because I was still quite young really at 44 to have a conversation [about things like] ‘if I don’t survive this, will you help bring up Katie?’ So that was the most emotional part of it, and also not being here for James as well, but it still is [frightening] because you still live with this thought in your mind, ‘what if it happens again? What if ...?’ and you can surround yourself with all the gadgets in the world to watch you, to monitor you, but there’s no certainty* (Diane: 409).

Dave made sense of his experience by stating how difficult and shocking his recollection of SCAs had been for him. There was more uncertainty of further arrests and not surviving them. His experience felt both real and that he was going through the motions. There is a deep sense of fear on one hand and making rational sense on the other. This is illustrated in his lucid comments to his wife, expressing love for her and the children as a final goodbye.

*I mean, just sheer terror, panic. I say panic, but actually it isn’t the right description. But, yeah, absolute terror and fear each time it happened and each time I came back I just thought, you know, ‘this is it, this will happen again in a minute and, you know, I’m not going to be so lucky and they won’t be able to bring me back’. So I remember my wife was there at the time; then I remember telling her that I loved her and love[d] the kids, if I don’t make it. That was my thought, [that] that was it. I thought I was finished, so, yeah, not nice* (Dave: 125).

A sense of detachment seems evident where participants felt separated from their experience. In a sense, it was as if it happened to someone else, particularly as they could not remember or picture the experience and what that felt like. *“It’s like it was happening to somebody else as though you were in a bit of kind of dream, really. It was very unreal, very surreal”* (Teresa: 507). For Teresa, there was a sense of being overwhelmed at her survival of SCA. Having been told by medical staff she was an unusual case, she initially felt she had to be strong and support her family, namely her husband and children, and protect them from her SCA event. She could not focus on making sense of the event to begin with and distanced herself by putting emphasis on things she could ‘do’ to distract herself from unwanted thoughts. These seemed incomprehensible at the time. She has now made sense of her coping mechanisms used at the time, as she reflected on how a few days changed her tremendously and altered her view on life.

*I think it’s so immense...your life is so changed in those couple of days that it’s just too much to take, you know, the whole lot in, um, so you get some sort of coping mechanisms and I can remember...silly things like, um, lip stuff, um I was saying, ‘I want a particular sort of lip stuff’ because it was sort of [laughs] and I was doing my nails and, um, I’d get some nice body wash* (Teresa: 552).

Diane had no idea how she should feel, given she could not connect a memory or felt-sense experience to the SCA. This sense of emotional detachment created further dissonance in terms of making sense of her thoughts and feelings around SCA, particularly as she could not visualise herself being part of it. *“You have no recollection, but if something happens, you can attach an emotion to it, can’t you, but because...something happened and I wasn’t emotionally involved and I didn’t know it happened, I couldn’t attach anything to it”* (Diane: 643). Some did not recount shock and had a more passive response, although still stating their disbelief in what had happened. *“I just kind of took it all in my stride, I guess. I don’t know, it was just I think it felt like I was living someone else’s life even though it was me”* (Wendy: 56).

### **5.1b. Memory gap**

This theme reveals what it is like to have a memory gap and live with what one cannot remember. It describes participants’ feelings around not knowing what has happened, feeling disoriented and needing to piece together the past, which is often fragmented. In particular, not having gone through the experience with mind and body recollection often creates confusion.

Participants spoke of their confusion at having scattered memories and not knowing where they were or what had happened during their time in the hospital. *"I didn't know where I was...I didn't know who I was, I didn't know what had happened. I just looked over and the first thing I knew positively was that was my wife"* (Nick: 26). Nick described how confusing it was for him and how he could not make sense of it until later. *"It was very, very, confusing...once they had established that my memory was intact I...within a couple of days I knew who I was, I knew who my family was, I knew where I was"* (Nick: 142).

Norman felt confused that hospital staff had not spoken with him. His experience of his mum dying from SCA in hospital created initial anxiety for him. Fear of the same thing happening to him further exacerbated his uncertainty. He made meaning by linking it up with a sense of aloneness and isolation experienced on the ward. *"I was confused. Why I got angry [was] because no-one came in to talk to me...so the nurses...I was in bed five [and] they would go one, two, three, four, six [and] then back out. I only saw them when it was mealtime, dinnertime"* (Norman: 109). Steve expressed much confusion regarding the first few months in hospital where he was unsure of what happened. He reflected on the extent of how serious his SCA event was in terms of the sense of how he felt altered by it. *"I had lots of things swimming around inside there [points to head] and lots of confusion about it all. It's not nothing to go to bed and then wake up in the hospital with people leaning over you telling you you've had a cardiac arrest"* (Steve: 118).

Feelings of confusion continue with Bill, who, without a memory, made assumptions as to what may have happened. He felt confused by not having a visual reminder, a pictorial memory he could connect to the experience. *"Not seeing it happen, I didn't really understand...[I] just thought I'd pull myself back together again...I just thought it would be something I'd get over, but at the time I didn't realise it was more than that"* (Bill: 96). Linda was unsure as to what was happening to her and hence found it difficult to assimilate. As she expressed her 'traumatic experience' now, there is still a sense of her remaining ambiguous and cut off from strong emotions:

*I didn't really feel anything because I didn't really understand what it all meant, because I was only 17. I'd kind of been through this traumatic experience [which] I was still quite disorientated from and I didn't really know what the long-term implications of it were going to be.* (Linda: 120).

Diane struggled without first-hand knowledge as to what had happened to her and why. Without a memory, her confusion seemed greater and she has been unable to make sense of her experience.

On reflection, she attributed her general uncertainty in life post-SCA to this ambiguity, feeling unable to derive meaning or assuredness from what she cannot connect to on a physical, cognitive and emotional level.

*There were two to three days missing out of that event, which isn't 100% filled in and our brains are, you know...we want to know everything, we want to know, to analyse...I'm quite an analytical person [and] I like to know everything...why did that happen? And why did that do that? And some people aren't, but I am, so I fight that* (Diane: 628).

However, for Wendy and Bill not having a memory translated into safeguarding, shielding them from negative memories of their experience. There is a sense that with less emotional attachment to a physical memory, Wendy was able to recall the event with distance. *"I can talk about it really easily and I don't really know why. I think because I was in a coma for the bad bit, it means I can talk about it"* (Wendy: 79). Bill felt that not having a memory of the event gave him licence to separate himself from the experience. In a sense, this became a protective element of his cardiac experience where he assumed a more autonomous role. *"I'm curious about what went on, but it doesn't trouble me particularly because I know that's what happened and when you've been through something like that your brain doesn't want to remember it"* (Bill: 157).

### **5.1c. Understanding of SCA**

This subtheme refers to how participants understood and interpreted their SCA without always having possible causes or clear-cut answers, and in particular, how they construed meaning and made initial sense of their experience.

Participants collected causal information in order to make associations as to what happened, and why things happened as they did. This informed and enabled them to understand their situation better by putting it into context. In particular, how events were justified and managed helped them to construe memories from their own or others' recollections. After 20 years, Nick still experienced overwhelming feelings of gratitude towards his boss who performed CPR. There is a sense that by understanding events, Nick has been able to construe meaning, from the intentions and parallel experience of his boss to paramedics eventually reversing his cardiac arrest. *"My boss Steve: I've thanked him a million times, but I still get emotional about this. He couldn't stand there watching me go*



*like that, waiting for an ambulance to arrive, as he lost his mother to a cardiac arrest a few years before, saw what the paramedics were doing and he just couldn't stand there and do nothing, so he started giving me CPR there on the street'* (Nick: 55).

Dave experienced his first SCA after contracting the chicken pox virus. He, therefore, knew the cause, which made it easier to comprehend. However, when suffering further arrests years later he did not have the same causal explanations, which made it more difficult to grasp. In a sense, it appeared more uncontrolled, as it could not be easily rationalised. There is also the idea that with increased uncertainty, normality was difficult to regain.

*I mean, it was associated with the virus going for my heart and that was it...you know, I could compartmentalize that and rationalize why it had happened as a result of that virus, so that was quite easy, I think, psychologically, you know, to put that to bed so to speak, and return to normal for that first one.* (Dave: 63).

A feeling of not being informed and not knowing enough about their health and what was happening to them was a recurrent theme. It revealed their sense of helplessness adding to anxieties. Teresa found it difficult to grasp her anxious feelings as they linked to not having enough information about the cause of her SCA. These helpless feelings in her narrative showed a vulnerability, which she found difficult to manage over time, with continual uncertainty about her physical health.

*Because I don't know and it makes me...I'm aware that I'm quite anxious about [my health]...yeah, there is a sort of anxiety level in me that I'm trying to cope with. I think really, um, it's got better over the years, but I think it's still there, that feeling...and I don't really know what you can really do about that feeling...yeah, it's not knowing the cause and yeah, the fact I had the cardiac arrest, that I was very, very ill* (Teresa: 128).

Teresa was told by practitioners that she was 'an unusual and unique case' which only added to her sense of helplessness. In a way, this made her anxiety and uncertainty more pronounced. She used humour to deflect the uncomfortable and perhaps painful meanings she has made from her abnormal diagnosis. *"Yeah, it is the feeling that I'm quite unusual, you know, and that adds to the anxiety I*

*think really...I sometimes think I wished I'd just had a heart attack [laughs], you know, but yeah"* (Teresa: 1198).

Diane felt initially she had little assurance as to what her SCA represented and hoped others, particularly medical staff, could give her information to make more sense of it. She felt her emotions unjustified and needed to know more as to how and why she felt the way she did. There was a sense of feeling isolated in her SCA experience: having to go back to her home and 'normal life' where she felt she had few answers. A need to face home-life, work and family after a tumultuous change in her life with reduced medical support added to this isolation.

*There's a lot of emotional baggage...because you still don't know why it happened, but they sent you home and you're like 'but you've sent me home! Why have you sent me home? I'm not better...you haven't told me why! Why did you send me home?'...So you come home with all this 'why'...why did it happen? And, um, so for the first week you are still in limbo, because you don't know what to do and what to think. Everyone is acting normal around you and it's not like you've been gone a night or two nights: you've been gone a whole month and it was really hard...and you've come back to the place where it happened* (Diane: 317).

Diane lived in constant apprehension and uncertainty. Her fight and anger translated into fear and difficulty in accepting what she could not be certain of in life. Not having enough information or knowledge meant that it was difficult to predict or prepare for future possibilities and gain a sense of control. *"We want to know to analyse...I'm quite an analytical person. I like to know everything...why did that happen? And why did that do that? And some people aren't, but I am, so I fight that"* (Diane: 630).

Harry too recalled not having a known cause for his arrhythmia, which became part of his anxiety and fear that he could not predict or control another arrest. As an avid sportsman and runner, this caused havoc initially where he was unsure how much he could do without risk of causing another SCA. In trying to make sense of his experience, Harry assumed some connection to sports and stressors precipitating further arrests. His anxieties seem entwined in managing the uncertainty of his physical limits.

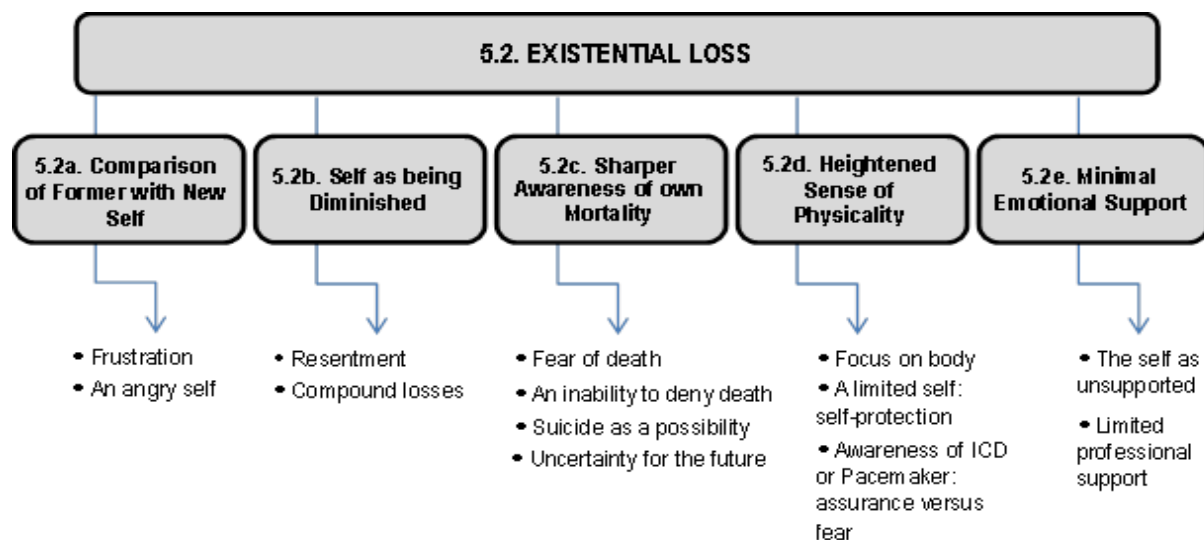
*I was told they did, like, every single test they could do. They didn't know, and to this day [don't know] what caused the arrhythmia. Um, that's part of my anxiety [that] I do have, is not knowing what causes it,*

*and it's sort of possibly adrenaline, sort of fear, which could be triggered by sport or [that] sort of stresses* (Harry: 91).

Not having a clear explanation for their SCA meant some received incorrect diagnoses and felt mismanaged. Teresa used nervous laughter to depict the ridiculousness of hearing how she had been lucky to survive and would not have done so years ago. This did not ease any anxiety she had, but put the focus on her 'would-be death' which was not helpful or compassionate in terms of aftercare and well-being. “[The] Doctor said, ‘ten years ago, you would have probably died’, which didn’t help me [laughs]” (Teresa: 1186).

Bill experienced an incorrect terminal diagnosis, giving him three years to live. He experienced much anger as he reflected on the abrupt way he and his wife heard this. This triggered them to seek further help and support elsewhere, and, coming from a medical family background, they felt confident to seek answers from other professionals. This provided some separation for him: in a pragmatic sense, he could take a step back by looking at his own situation as a patient and that of the service provider. This focused him on their role and responsibility in an attempt to protect further harm being done to his family “I was told [I had] three years to live with no warning whatsoever. [It’s a] beautiful piece of patient management, that...how to depress your patient in one easy step” (Bill: 686). His own well-being was often negotiated and entwined with that of his family, namely his wife, who sometimes reacted anxiously to changes in his health. This influenced his own sense of anxiety, stress and fear, which seemed commonplace to him.

*Support for the family members is as important as the support for the person who comes out of it, because if the family is functioning better, there will be less stress on the person who has the condition, and it also stops problems developing on others, and stress on the person who has the condition. So, it’s, you know, you’ve got to look at it all round, otherwise you’re not going to get to the bottom of it* (Bill: 799).



## 5.2 Existential Loss

This superordinate theme revealed what SCA has represented. The themes that stood out across participants were of personal loss. These centred on a change of personal qualities and physical restrictions, creating a loss of normality. These sense of losses to health, normality and security created feelings of frustration, anger and resentment at times. This meant their level of emotionality had also changed, as they found it difficult to manage a myriad of feelings. This also created a sense of not having enough emotional support, as well feeling vulnerable and alone in their recoveries. These were experienced in varying degrees as a response to managing life after SCA.

Managing felt losses to physical health meant more awareness of their bodies, which led to more pre-occupation with self-protecting, and at times limiting activities. There was an inherent new focus on their mortality and facing the possibility of irreversible death. In turn, these deep existential losses created feelings of helplessness, fear, anxiety, isolation, dislocation and alienation. This had different interpretations where some felt more loss than others, which often resulted in a personal sense of self being diminished. These sub-themes are described further below.

‘A comparison of former and new self’ was present in seven participants and ‘self as being diminished’ represented in eight participants. This varied according to perceived changes to their lifestyle, functioning, emotional and relational support, self-management and increased awareness

of physical health and mortality. It included how they viewed themselves before and after SCA. Some experienced a diminished and limited self with compound losses. This loss of former self included changes to physical capabilities, memory loss and how they experienced emotions.

‘A sharper awareness of own mortality’ was represented in eight participants and meant feelings about one’s own death, including fear, were confronted and continually negotiated. A few considered suicide whilst undergoing difficult life changes in the early stages. There was ‘a heightened sense of physicality’ and increased focus on the body present in six participants. There was an attempt to monitor physical well-being by limiting some of their activities and environments in order to avoid the risk of another event. A majority of participants were more acutely aware of the unpredictability of another arrest by the visual reminder of an ICD or pacemaker provoking a further need to protect oneself.

‘Minimal emotional support’ was present in seven participants, in which they reflected on their experience of being let down and unsupported by family, friends and/or professional staff. This led to changes in how they viewed some of these relationships. In essence, most participants experienced changes in how they related to people who had not met their expectations.

### **5.2a. Comparison of former with new self**

An overarching subtheme amongst participants is the comparison of their former self with the new self-having emerged after SCA. They reflected on qualities and abilities they felt they had and were important, in light of what now felt lost and unobtainable. This comparison brought up emotions of frustration and anger, further discussed below.

There is a sense of frustration when participants recounted what had been lost to them. Dave felt his loss of spontaneity meant he had reduced freedom in what he chose to do. His decisions were thoughtfully planned as he focused on minimising further risk to his health, in order to avoid being in an uncomfortable environment or situation. In parallel, his sense of avoiding these situations where he could feel powerless allowed him a certain freedom to minimise anxiety and tension:

*I used to go up in town, work in town and on the trains and tubes and everything else. I don't like it anymore at all, I just don't like it, and yeah, that causes me anxiety and again I don't know why. I suppose*

*it could be something to do with the fact that if I had an event on the train...umm...you're stuck aren't you? Or if the train breaks down, as they quite often do, they get stuck somewhere, you know, and it happens, I'm done for* (Dave: 403).

Teresa saw herself as a fit person who enjoyed a teaching career, but after her SCA felt this had changed. A loss of career and not being a fit person anymore meant an altered sense of her identity in response to which she sought to create new meaning and make sense of her changed life. Her sense of living with anxiety highlighted the important existential focus she now had on health. However, a confrontation and new awareness of constant uncertainties left her in an uncomfortable and anxious state at times. *"I get anxious sometimes about the kids, but I don't get anxious, I don't think about things that I think don't matter. The anxiety...I've never had that, before I was ill, I never had it. I felt very confident and fit"* (Teresa: 1115).

Linda is frustrated at having to adapt to a new self, suffering from memory loss. She challenged this by creating visual photographic reminders of her family over time. *"The ones that are really important I have to revisit because I think that's the most frustrating thing, is, will I forget some of the important things in the future? So yeah, if I have plenty of experiences, then there's always going to be some I can remember"* (Linda: 1178). Steve has made sense of his experience and changes to self through his ability to have freedom to control his life and body. *"It's quite a profound change to find that one day you're in control of your life...then all of a sudden you're in bed [and] you can't move"* (Steve: 499).

After losing his coach licence and career, Norman felt his life lacked purpose and meaning, to the extent that he despaired. His career had meant a lot to his sense of duty and value as a person. In particular, being of service to others gave him a sense of pride in having a purposeful pathway. His sense of helplessness and dislocation made it difficult to accept a new self, especially as he over-identified with his job and social connotations.

*I just feel lost, you know...no purpose anymore...I wouldn't mind if I died today* (Norman: 573).

*I get more frustrated about not being able to do stuff...not being able to work...my job was my life...I used to do 16, 20 hours a day... [long pause] it's gone...I used to love making people happy...when you take them away for a 10-day tour all around Italy, and you bring them back, and you see the smiles on their faces...you've done your job right...and that's gone!* (Norman: 339).

Diane also struggled with a changed sense of self where she compared her previous perception of herself to her current situation. She felt negative about losing qualities she previously felt she had and now viewed life differently. *“The biggest thing that I hate out of all of it is that I’ve lost who I was, because the changes to me are very big, they are big changes”* (Diane: 729). Her sense of loss is expressed deeply in that her SCA experience had not only limited her, but prevented her from living a life previously envisioned. The changes to her physical health had a knock-on effect in other areas where she began fastidiously to control her external environment. This made it challenging to accept her ‘new self’. *“The person that I was I had plans and visions of where we were going as a family, but also as an individual as well, and now I’ve become a control freak”* (Diane: 894).

Harry felt particularly angry when his ICD activated years later, experiencing his second arrest. He had worked hard on improving his physical and emotional health. He experienced his sense of self as having improved progressively since his first SCA and felt he had regained much control over his life. After this incident, he regressed back to earlier years and a former self – one where he struggled greatly. The anger about the uncertainty of life, at not being able to predict or control future SCAs or risks to his health was apparent. *“I can’t believe this happened and why has this happened? And I just feel angry, you know. I had got myself back to more or less to where I was pre-2007 and it’s come and hit me again”* (Harry: 389).

### **5.2b. Self as being diminished**

The subtheme the ‘Self as being diminished’ represents participants’ sense of ‘being and identity’ being lost with less ability to achieve previous aspirations.

A sense of resentment was present. Dave felt he was not in a position to look to the future and make plans, as there was potential for him to have further arrests. This limited his outlook and made it difficult for him to regain a sense of autonomy in life. He felt loss at a deep level where much uncertainty existed. *“It’s not very nice, because again it diminishes your thoughts, aspirations, your goals and whatever else. My thoughts are just [to] survive each day, live each day”* (Dave: 465).

Although Diane had planned to have more children, her decision not to after SCA was difficult to accommodate. She begrudged having to alter her life plans and felt SCA had taken much from her. In a way, there was a sense of multiple losses for her, making it difficult to come to terms with.

*“At the time that I had my cardiac arrest we were trying for another baby ... we didn’t want to go down that route just in case it made me unwell or the baby was at risk, so there’s something else that I’m bitter about”* (Diane: 818). Her sense of resentment at the unfairness and randomness of it happening to her unexpectedly given her young age meant it was harder to accept. Diane used the metaphor of ‘baggage’ where she revealed the overwhelming burden of her unexpected SCA.

*Normally these things happen to older people when they are retired, so they can sit around and relax and recoup and do those things. Why couldn’t I? I had to go back into full life, work, look after my daughter, run a home, um, so I look at it now and think [about] the baggage that came with it. I didn’t have time to heal really, emotionally heal...I just had to get on with life and that itself has a little knock-on effect because, you know, it’s such an enormous event in our lives, [in] all our lives. It touched all of us differently* (Diane: 495).

Linda, being younger, used avoidance, particularly after the first few years where she disregarded her physical health and acted out her ambivalence, adopting a careless lifestyle, including frequent alcohol and drug use. She challenged her sense of self at the time, having incorporated what she felt was lost. In a sense, she further lost herself in very risky behaviour, expressing fight and challenge, where she felt many people (namely friends) were ambivalent to what she had gone through.

*I think the fact that I could never really have a life because I couldn’t have children, I kind of said I wasn’t going to have children because I had a very high percentage of passing on the Long QT to my children, so I kind of thought, this is it, this is me. I’m going to go off and do what I want to do and to hell with everybody else, really* (Linda: 200).

For some male survivors, their SCA represented an emasculated self. They felt the experience had altered or minimised their capacity to function in their gender role. Steve had been a business owner for many years and travelled extensively. He was used to being fit, independent and supporting himself and his family. He saw himself as the stereotypical male, a strong provider, and this made his experience after SCA particularly difficult. The suddenness and enormity of changes to his life physically and emotionally meant he found himself in a most vulnerable position. This was difficult to accommodate, challenging his self-perception. *“It’s all snatched away, unfortunately.*



*You no longer can do the things that you could do, so you feel emasculated, um, dependent, um, fragile, um all the things that macho males don't like*" (Steve: 171).

Nick also took his financial and emotional responsibilities seriously and focused on regaining a sense of his old self. He was used to being a strong provider for his family and it was difficult to have his driver's licence revoked. He used sarcastic humour, suggesting his perception of adult male role/provider had been demeaning. His lack of control and helplessness in supporting his family is evident, as is a personal sense of responsibility for another.

*I'm a good [giggles] little boy. I wrote to the DVLA and let them know what was going on and they said 'we'll get your case documents from the doctors and let you know' and two weeks later they pulled my driver's licence and it took me two-and-a-half years to get it back. So, um, my wife started driving for everything and everyone and um... that was a wallop in the head for sure that was...I couldn't work* (Nick: 170).

Diane had to manoeuvre life in a very different way after her arrest. The knock-on effects also included weight gain. The sense of fear around exercise resulted in her becoming more housebound, which compounded her sense of anxiety and self-image.

*So you sit a lot and as a consequence of sitting a lot and the medication that keeps your heart beat low, you put on weight and I have, I've put on loads of weight and then that has a mental effect. You look in the mirror: you don't like yourself, the way you're looking, but you're too afraid to do anything about it* (Diane: 563).

Harry also expressed his reluctance to accept what had happened to him and experienced fear and anxiety in his day-to-day life. This meant he refrained from leaving his home and doing sports. Consequentially, he put on weight and became reclusive. This had overwhelming effects on his emotional health in terms of anxiety and isolation, and he sought counselling. He eventually began to leave his home and to exercise. *"The first two years after it initially happened I didn't want to do sports again, I put on a lot of weight and then I sort of had anxiety"* (Harry: 145).

As well as a multitude of losses to self, some experienced bereavement before and after their SCA. In these further compound losses, participants recognised the impact of a loved one's death on their own lives. Teresa illustrated this below where she felt her 'other death-related' experiences in life, namely those of family members, had contributed to anxieties and fear of her mortality.

Trauma, bereavement and the suicide of younger members of her family in her formative years had reminded her of her recent brush with death. Her experiences have signified an acute awareness of fearful change and fragility.

*I was a student and my auntie died quite young, in her fifties, of bowel cancer, and I remember her dying and that was a very, um, yeah, that was very significant...this part of the whole emotional, um, just at the beginning of 2008, January, so it was only a very short time after, um, my brother committed suicide. Then my uncle got Parkinson's and he died just recently and very sadly my brother-in-law has been diagnosed with Alzheimer's and he's just a bit younger than me, it's early onset...sounds like a tragedy, but this is all contributing to it (Teresa: 914).*

This parallel experience for Teresa has been part of her emotional journey, which has surfaced anxieties about her own death and how suddenly it could happen. *"He wasn't there for very long...there was a man in the bed next to me slightly younger than me and, um, he had a cardiac arrest and he died from the cardiac arrest and that had and has had quite a profound effect on me, really. I think of him a lot"* (Teresa: 1338).

Norman identified with his mother who had died of SCA when he was seventeen. He recounted his experience and noted that he needed to move on. This common ground gave him a sense of assurance where he now has found peace in being able to talk to her. *"I go out in the back garden when I'm feeling down and talk to my mum and ask her 'why you and not me?'...you know, it's just the way I feel"* (Norman: 577).

### **5.2c. Sharper Awareness of own Mortality**

This subtheme revealed how participants felt about being so close to death. For many, this brought about a fear and a feeling of unsettlement in having faced and survived a loss of life once, it could happen again. The uncertainty of life was now experienced deeply, in a sense a living with limits.

Dave felt afraid and was constantly aware it could happen again and at any time. His fear was such that he challenged it, forcing himself to do things he wanted to. In a sense, his 'fear of fear' around isolation became stronger as he sought to gain autonomy by not letting it overpower and control his social life. With increased uncertainties around his health, his choice to normalise his life as

much as possible helped minimise feelings of isolation and gave a certain element of stability and autonomy. This enabled him to manage life.

*[You feel] fearful and aware of your mortality [and] the fact you have no control...um...I suppose...other than that, I try to stay as grounded as I can and carry on as normally as I can. I think that's important. Just to get out there and do stuff, because you can become...I think my belief is that you can become very insular and even agoraphobic, and it's a very quick path to getting like that (Dave: 380).*

Bill showed concern for his own mortality and reflected on the probable consequences to the family had he not survived. In a recent parallel of events, Bill's brother-in-law died of SCA. This had a particular poignancy for him, as it stood as a reminder of what could have been their outcome.

*It's hard. It hit me, because, I know I didn't intend to, but I actually carried his coffin into the church and that was quite a struggle for me. It was incredibly heavy, but I thought [of] all the things I ever thought I'd be doing, carrying my brother-in-law's coffin into the church was not one of them. That's when you do start to wonder what if that was me one day, you know. That was a really strange thing to happen. We're kind of still adjusting to it (Bill: 863).*

Teresa also expressed her increased awareness of her own death as a result of having been so close to it, and her realisation that it could happen at any moment. In her sense-making, she interpreted death as 'out there' in terms of it coming towards her like a separate entity. There is an element of fear and helplessness having squarely faced death, which gave further confusion. She found it difficult to make sense of her new focus on her health.

*Oh yes, you know, the fear levels are there, I think because of the cardiac arrest, yes. Yep, around mortality really, the fact that you could just die, it's that feeling that you did almost die, that death was there and, um, then I wouldn't see my kids really. I think really it was the kids, yeah, so somehow in my brain that comes back [laughs], it just comes back. Yeah, yeah, and it's the fact that there's really nobody around that really understands. I've tried with a few friends and they're lovely, but they don't really understand the feeling, and I don't really understand myself really (Teresa: 215).*

Wendy has had more thoughts about dying and the 'what-if scenarios', which created much unease for her. Her fear physically translated into unrest and insomnia, and she constantly reminded

herself that it could happen again. In a sense, her feelings of helplessness were exacerbated by the meaning (“awful and negative”) she placed on her constant thoughts. She negotiated those negative and fearful thoughts and feelings by questioning how valid they really were, given they occurred when she was not able to sleep. This provided some reassurance. *“I get insomnia for short periods and when I get that it’s just awful. You just lay there awake, thinking about death [and] wondering what’s going to happen, you know. Am I going to die again? And just stupid things like that”* (Wendy: 1371). Harry too experienced high levels of fear and constant awareness of his mortality and putting himself more at risk of another SCA. *“It does make us think about dying and people who’ve died, so to speak. Again, I just sort of push it to the back of my mind and sort of let it go...I think the fear is not a normal feeling. It’s the thing going off again as well”* (Harry: 588).

Diane experienced this closeness with death as now having the first-hand authority that it can and will happen at any time. Having squarely faced this reality, this created a constant fear of death, which was difficult to evade. This was at the forefront of her day-to-day living and meant she was regularly reminding herself and experiencing intense emotions of anxiety and fear.

*I mean...it makes you afraid of dying. I know that, and before, if you [had] asked me, I was never afraid of dying, never. If someone said...I’m not afraid of dying, it’s fine, but when you come that close to it, um, I’m...I’m...I’m totally scared, because I know how quickly it can happen* (Diane: 512).

Steve expressed the realisation that it may happen again. His attunement to and engagement with his own death showed a different perspective, in which he attempted to fulfil and achieve goals in life. This focus on time and fulfilment appears driven by a sense of fear and helplessness at his life ending. In a sense, he has gained autonomy by having a sharper pursuit of accomplishing desired experiences in life.

*There are things I’ve always wanted to do in my life and never had the opportunity to do, and now I have, so I’m going to try and realise that...I mean, the thing about it is, what’s started to scare me as well is that I’m 59, so I’m bordering on 60 now and getting to that age where my health is declining, and, um, I’ve had a SCA. I might have another one. I might have a terminal one* (Steve: 736).

A few participants mentioned suicide as a possibility. The paradox of life, death and suicide is important. Surviving an untimely SCA is rare. This interplay of life and death after such an event

can seem unavoidable. Norman and Steve, faced with the unpredictability of major life changes, felt powerless. This led to both having ideations about or making attempts to take their own lives.

Norman felt unsupported and unheard. His experience was one of despair, anger and loneliness at the many life changes he faced without a sense of control. It was difficult for him to make sense of his experience where difficulties faced in day-to-day living seemed to engulf him. In a sense, his isolation and depression appeared construed in having lost parts of himself he heavily identified with. These included a discontinued much-loved career and having a purpose in life. There is also a strong element of not being acknowledged: an alienation from a society where he struggled to gain monetary and emotional support, which led him to question his reason for living.

*Nobody believed me and I was just getting depressed...you know, I tried to take my life, and my son found me and called the police and I got arrested and put in a mental hospital...only overnight...they talked to me and they calmed me down and everything...they said they would help me [and] they contacted the benefits people (Norman: 190).*

Steve too faced impending physical and mental constraints after his SCA and felt impoverished. The many changes to his health and lifestyle meant it was difficult for him to accept, and he expressed thoughts about ending his life. This changed as his health improved. He was then able to accept and accommodate his experience, which altered his life-view. The sense of paradox of surviving death and then wanting to commit suicide suggested a deep-seated powerlessness in individuals who had previously perceived themselves as very much in control over their lives, physically and emotionally.

*It sends you into a mild depression sometimes, an acute depression, really. You do think about suicide, um, I did. I still do occasionally, um, there's an acute loss of dignity involved in all of this and, um, I think for me I always felt and I still do feel that if I ever got to the stage whereby I was wholly dependent on other people to exist I'd rather not exist so, um, suicide...suicidal thoughts are very common earlier on (Steve: 189).*

## **5.2d. A Heightened Sense of Physicality**

This subtheme refers to participants becoming acutely aware of their physical body and felt changes because of their SCA. These changes were predominantly around breathing and heart rates and the presence of an ICD or pacemaker. They found that having this constant awareness

or focus on the body meant they were monitoring themselves regularly and self-protecting, which also created a sense of anxiety and continual fear. The ICD or pacemaker, viewed by many as a safety tool, enabled assurance and allayed fears of another arrest in some, while in others fear was increased.

Many participants listened to their heartbeats often and monitored themselves for anything unusual in an attempt at safeguarding. Diane sought to allay fears of another arrest by constantly checking her heartbeat. This became synonymous with her post-arrest. *“I know it’s a weird thing to say but...I can hear my heart beating; not so everyone else can hear, but you’re so attached to your heartbeat because you’re so afraid that it’s going to go wrong again that you constantly listen to it”* (Diane: 524). Harry also expressed that he constantly checked himself, noticing his heartbeat and aspects of his body in response to fear of further arrests. He counteracted this fear by repetitive behaviour, which diminishes his emotional responses, in a sense enabling him to gain some element of control. *“I felt everything, every beat of my heart for a good six months afterwards... you’re constantly looking, you become desensitised to that area because that’s what’s going to happen and it’s about control”* (Harry: 267).

Nick too felt that his SCA gave him a sharper attunement to his physical health, which meant he assumed more control over aspects of his health. This increased awareness gave a sense of individual responsibility and autonomy as his SCA had precipitated interest in monitoring his health. *“I have become super sensitive. I know if my heart’s missed a beat; I know if my breathing has become irregular; I know if something doesn’t feel right”* (Nick: 962).

Nine participants had an ICD implanted, and only Teresa had it removed. A tenth participant, Linda, had a pacemaker instead. For most participants, these devices became a safety measure and gave the assurance of knowing it was there to help them survive another arrest. Wendy felt grateful and trusting in her ICD. This gave her a sense of containment and she could displace her fears about death. She linked her thoughts and fears about dying to when she did not have her ICD and therefore considered it most valuable as a psychological and emotional measure. *“Once it was in and healed, everything for me had mentally changed. I went from thinking about dying all the time to being more positive, but my ICD made me, um, I don’t know much...much more confident with everything”* (Wendy: 660).

Linda expressed her confidence in the device and felt protected and assured knowing it would immediately assist her if needed. She felt comfortable with the pacemaker, as she had not experienced another arrest in 20 years and feared to have it removed or replaced with an ICD. Her trust in the device keeping her alive created a fear of change. This brought about uncertainty, which disrupted existing perceived securities, thus created a sense of anxiety.

*I suppose I've kind of thought I found my balance. I've found what works for me. I've found every 6 months going into hospital to check everything is okay is perfectly fine, the boys get checked every 6 months [too], so we've kind of found a routine that works for us as a family and to then go and change something I think would probably make me panic, in the fact that is it all going to go horribly wrong (Linda: 722).*

Harry alluded to the dual aspect of the device in that it is a constant reminder of what has and could happen again, but also acted as protection, enabling him to have a better chance at survival. There is also an element of there being no pain, again another protective and sustainable factor, which addressed the potential of the device causing further harm. *"It's just more sort of permanent in your mind that something could happen, but then again, um, I've got the ICD, so it's good...it didn't hurt either. That was the other thing I didn't mention, because when the ICD goes off, it can hurt like hell"* (Harry: 464).

Similarly, Teresa felt lucky having an ICD that would prevent her dying, but also felt it was a constant reminder and feared it going off. *"I limit myself I think, because I'm frightened and that's more when I had my ICD"* (Teresa: 746). She expressed this constant tuning into her physical health as tiring and taking up a considerable amount of time. This sense of preoccupation with health illustrated a level of helplessness where fear and constant checking drained her energy levels and limited what she attended to in life. *"I'm super tuned too, if I'm feeling weaker, you know, so it does affect life to a large extent and I do get very tired"* (Teresa: 1147).

### **5.2e. Minimal emotional support**

This subtheme is about participants not having received help and support from those in their social sphere, including family, friends, and colleagues. This has often led to feelings of loneliness and isolation where they have not been able to speak with others about their experience. There is also an acknowledgement of limited professional support where counselling or psychotherapy had not been offered to assist their emotional adjustment. At times, they expressed a lack of practical

help getting disability or other allowances. This felt invalidating where the seriousness of their condition was unacknowledged.

Teresa felt unsupported and let down by her husband, whom she had hoped would have been a stronger support for her, rather than becoming emotionally overwrought.

*I actually needed him to be next to me, holding my hand, saying "you're going to be alright" and get me to the ambulance, and he wasn't there [sobs] and I kind of feel I wanted him to be, and [instead] he was sitting over there crying. I think, "well, I don't know whether I'd be crying if it were the other way round". I don't know, but I'm being really quite harsh on him really, poor fellow, but that's how I feel and I can't get around my feelings (Teresa: 998).*

Linda felt matters with her sister got progressively worse after SCA as her sister became jealous of Linda's close relationship with their mother. She made sense of this over time and used the analogy of SCA 'nailing' what was already there, cementing her sense of further loss.

*My sister's jealousy got so bad that I've cut all ties with my sister, so that's the kind of element that I think started...although there was always some relationship issues with me and my sister, I think that was the kind of final nail really, I think with everything that happened. Um, I'm okay, okay actually, because I think I've moved on from it, because I kind of felt like actually, I needed people around me that were positive and could keep me kind of in the direction that I wanted to go and I felt that she didn't do that (Linda: 263).*

Bill and Wendy both expressed that they had received a lack of support from colleagues who they felt were not empathic nor acknowledged their SCA experience. Bill felt upset by having recognised how his experience had been minimised.

*There was a stressful time with them just before I left them, and, um, you know, no-one came to the house or went out of their way to see us. I've met a couple of them since, but they've not made any fuss about this to be in touch particularly, and I worked there for a number of years, so this is rubbish...people find it hard to deal with (Bill: 441).*

Wendy was given lighter duties at work, which consequently encouraged some colleagues to ignore and treat her badly. This meant her work experience became such that she was unsupported at a



time where she felt most vulnerable. There is a sense of helplessness in her description of her personal experience of SCA, which was not self-inflicted or chosen, and nor were the lighter duties. This made the incident all more difficult, creating confusion and disappointment.

*Why are you being a bitch to me? Like, I felt really let down, I suppose. I felt, it's not me that's put these restrictions on. I haven't been all high and mighty and gone "I'm not doing this". It's the company that you and I work [that] for have sent me to occupational health who insisted I don't do x y z (Wendy: 1053).*

Experiencing a lack of emotional support caused some participants to feel alone and isolated. Steve felt judged and unsupported by friends who dismissed him after his SCA. His isolation led to a challenge of earlier beliefs and expectations about his relationships with others. He appeared to minimise and subdue his own needs and expectations of others, which showed ambivalence. In a sense, he was self-protecting for the future.

*I felt really isolated and what became apparent to me was that people were putting far more importance on the fact that I had an affair than I had the cardiac arrest and, um, I mean, you know, I kind of [long pause] [had] gone through the trauma and the internal turmoil over that, and I came out the other side thinking, well, I'm lucky in lots of ways, I'm lucky that I found out that some people are more shallow than what you think they are and, um, you can't really expect [much from] or rely on other people (Steve: 611).*

Participants mentioned limited professional support in terms of their emotional health and well-being. Many expressed how unsupported emotionally they felt after being sent home from hospital and surgeries. They stated that if they had been able to talk about their thoughts and feelings after a potentially life-altering experience, it may have helped them in their transition.

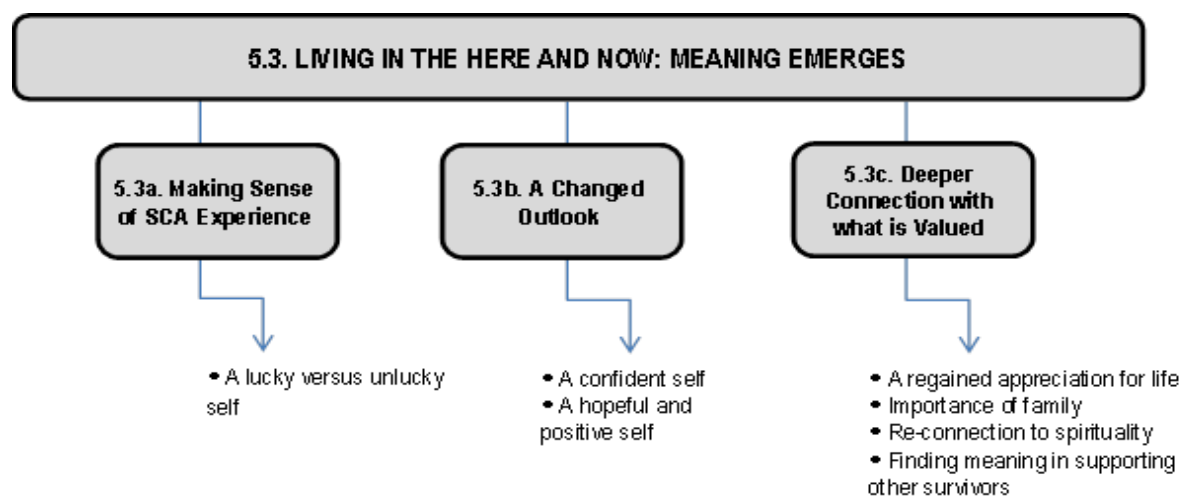
Nick alluded to having no emotional support and having had to sort it out for himself. There is a distinct sense of needing assurance and not having had the opportunity to talk it through. This created feelings of anger and isolation.

*They say "see you in three months" and that's IT and so you're left dealing with it...I don't have guilt about why I survived. I've sure there are people that are [feeling guilty]. I was happy I was still walking around, but I wanted to get on with my life, which had been interrupted for a good few months and I did, but I did it by myself with my family (Nick: 228).*

As a result, Nick fought hard to work it all out, which showed his resilience. *“I think it was my ability to cope with it. I had to come up with the solutions myself without any outside help and, um, I like to think I’ve done successfully because I’m walking around making sense now”* (Nick: 757).

Diane also expressed this sentiment, feeling isolated having to go home without emotional support or anyone to talk things through with. This lack of ‘talk’ and emotional support translated into a lack of care:

*As I say, no-one came to visit me, no cardiac nurse, nothing. It is emotional because you come back to the house where it happened. In the hospital, you don’t really think about it because you’re not surrounded by the things you really care about or have a real attachment [to], but when you come home then, with your husband, and saw my daughter, then it hits home what could have happened if that ambulance hadn’t been literally passing the road.* (Diane: 363).



### 5.3 Living in the Here and Now: Meaning Emerges

This superordinate theme brings together what it is like for participants to live in the here and now after their SCA in terms of how they have made sense of their experience and what meanings they have created. How they viewed themselves and their outlook on life is represented within themes of increased confidence, hope and positivity. This followed a deeper connection with what they considered important and of value, with particular emphasis on a stronger appreciation for life. The subthemes are further discussed below.

The themes that stood out across participants were making sense of their experience. ‘Making sense of SCA experience’ represented six participants. This involved juggling a sense of feeling lucky and grateful to survive, but unlucky in the first place to have a SCA. Most participants revealed that, although it was devastating living with the impact of SCA, they all experienced an urge to make the most of life and search for meaning in this second chance.

‘A changed outlook: increased confidence, hope and positive aspect’ was found in seven participants, in whom a change in emotions was linked to a difference in outlook, and they expressed a regained enjoyment of life and appreciation for it. Many felt it gave them confidence and a drive to live a more authentic life, with sharper awareness of it being limited. Hence, a second chance meant an opportunity to live better.

‘A changed outlook: deeper connection with what is valued’ was present in nine participants. Participants expressed what is of value to them through their gratitude for and importance to loved ones. Many expressed the support and increased awareness of building close bonds with certain family members. There is also meaning found in the social aspect of supporting other survivors. Using their own experience and sharing information enabled them to be part of a communal group. All participants in this study belonged to online support groups in which there is a clear recognition of the need for peer support amongst survivors. In some, a reconnection with spirituality, expressed in terms of religious beliefs, helped support their meaning-making.

### **5.3a. Making Sense of SCA Experience**

As mentioned, this subtheme related to participants feeling both lucky to have survived the SCA and unlucky to have had it in the first place. This duality of ‘a lucky versus unlucky self’ is discussed below in terms of feelings created and a search for meaning in having a second chance at life. A majority of participants looking back after their experience felt lucky to have survived.

There is a sense of meaning created from the balance between an unlucky self, where one has had a serious threat to life, and feeling lucky to have survived what the majority do not. *“You’ve survived [and] you’re lucky to have survived. You’re unlucky it’s happened in the first place, but you’re lucky to survive, so it balances itself out”* (Harry: 620). Bill is able to rationalise the ‘bad luck’ negative connotation and

minimises this, in favour of having survived. “Yes, I’ve had slightly bad luck, kind of thing, happen to me for no apparent reason, which is frustrating, but by the same token I’m still here” (Bill: 271).

Wendy’s experience is heavy with positive emotions where she compared her challenging situation with what could have happened. “I mean, I feel like I’m unlucky, I guess, but at the same time really bloody lucky because it...there’s so much that could have gone wrong...everything...my outcome could have been completely different, but it wasn’t. I had positive after positive” (Wendy: 1243). Steve expressed his sense of survival as an opportunity not to be missed, gaining from it not only feeling lucky, but a second chance. There is a sense of feeling grateful where this second chance opportunity is highly important.

*I’m just very mindful that it’s very fragile, but I don’t, um, I never did think “why me? Why did I survive? Why am I here? Am I supposed to reinvent life?” Or something like that. I don’t think anything like that. I just think, well, “I am here and, um, I’m lucky”. I think I was lucky and, um, I also think that, um [long pause], more than anything else it’s not an opportunity to be passed on by* (Steve: 836).

Diane expressed having been ‘looked after’ by a higher source. She made meaning of her situation by her belief in a pre-determined existence: that there was a designated time to die for all. “I truly believe it wasn’t my time to go and I do believe that someone was looking after me that night, you know, and a bit of luck...I believe we all have a time to go and it just wasn’t my time” (Diane: 873). Dave experienced anger and resentment at being one of the ‘unlucky ones’ to have had SCA. However, he counteracted this with feeling lucky to be alive. This focus on having a second chance and fulfilling opportunities allowed a sense of autonomy where he was able to choose what he could control in life.

*Emotionally, obviously you do have dark days or moments. That’s where you really think about it, but I always used to think I’ve been very lucky I’ve got this second opportunity, so let’s not waste it* (Dave: 181).

*It would be very easy to dwell upon it [and] feel sorry for yourself, and I think a lot of people do that, but I don’t. I just think, well, it has happened [but] I cannot change that fact. I’m a bit pissed off that it did happen, obviously, and sometimes you think “why me?” [louder], but it’s happened and I’ve survived it. I need to, um, make the most of my second chance* (Dave: 430).

### 5.3b. A Changed Outlook: Increased Confidence, Hope, and Positive Aspect – The Authentic self

This subordinate theme represents participants' outlook on life after SCA. This included how they now viewed themselves, perceived changes and what they may have gained by this experience. There was a sense of having built confidence and inner strength in going through the SCA experience for many participants. This feeling now helped them navigate through life with an added sense of knowing what they were able to achieve with a more authentic attunement. There was a sense with Teresa that, having faced the ultimate certainty of death, she could be more assertive and definite in other decisions in life. There is also a certain confidence and strength, which she has taken from her SCA experience. *"I can be more definite, I can be more confident, I think. Um, I wonder if that's strength inside the confidence?"* (Teresa: 1081).

Teresa felt she became much more relaxed and allowed herself to have more freedom in self-expression. There is a sense of living with a more authentic self, which translated to strength in character. *"The change in me is that I'm more spontaneous, because I used to be more careful. I'm sillier, I'm letting my silly side come out"* (Teresa: 1436). The element of positivity regarding her outlook since SCA has given an added emphasis on getting more out of life and enjoying moments. *"I think I'm much more of a positive person, I really enjoy moments, yes"* (Teresa: 878).

There was a deliberate focus on what they had control over in order to help them progress in life after SCA. On reflection, they could see their strengths more vividly, which helped them through. They now used this gained awareness of their strengths to help them in their day-to-day lives. Wendy expressed this in terms of gaining strength from her recovery and enduring pain, having a sense of stronger 'self' or character. *"I learned I'm a lot stronger than I thought I was, um, after always being a complete wimp pain-wise, um, but I'm actually not a wimp at all and I'm quite hard now"* (Wendy: 1293). There was also a sense from Harry that a balanced approach supported him between continual fears of another SCA and renewed appreciation for thinking positively. This included doing what was important to him in life. In a sense, by focusing on what he enjoyed doing and not limiting himself, he was able to create autonomy and manage his sports. *"That's what I've got to deal with: every time I go for a run it could happen, but it's like sort of thinking positive"* (Harry: 443).

Steve acknowledged how challenging an emotional journey it had been for him. This included making meaning out of his SCA by reassessing his life plan. This gave him strength and helped him focus on what was important to him. There was a much sharper awareness of how he lived. This enabled him to manage aspects of his life and confront purposeful activities and wishes in a deliberate manner. *“I’m very mindful that I’m here for a very limited amount of time and it’s just up to me really to do what I want to do, and I can either do nothing and waste a gift or I can do something with it and try and achieve something on a personal level [...] so that’s what I’m doing”* (Steve: 714). By focusing more on what he valued, his outlook became more positive, which allowed him to gain a different perspective on how he lived. *“I think my future is really positive, more positive than it was before, um, more positive than it was prior to the SCA”* (Steve: 871).

Linda made sense of it all over time, whilst accepting that it had been part of her life story and that it made her who she was. This enabled her to stop fighting or avoid difficulties, and hence she embraced life with what she still hoped to achieve and experience. She was able to assimilate the experience by having internalised it as part of her lived experience. She remained hopeful for the future and managed what she could control, rather than what she could not. *“I’ve made sense of it because it’s made me who I am really and I think it would have been a different story if I wouldn’t have accepted that it was a part of me, because then I think you’re always fighting against it”* (Linda: 1109).

Nick, too, expressed a changed attitude: he was grateful for having the strength to alter his ways to focus on living more authentically, closer to his wishes. In a sense, there was a sharper self-awareness, which enabled more perspective on what was important to him in life. This gained awareness allowed him more attunement with emotions and expressing them. There is also an element of hope, gratitude and directness in being open to place value on what he deemed significant. This added to owned feelings of self-expression.

*It’s inside that my attitude is altered and, um, I’m so grateful for where I am* (Nick: 607).

*If someone is telling me about something that’s very important to me, whether it’s good or bad, I’ll start crying and I never used to be like that, and that’s, that’s occurred since 1994, and, um, I think I feel things more deeply because of what I went through and, um, I just care more about things. I think it’s tied up with it [the SCA]* (Nick: 979).

Bill felt much more confident, particularly in confronting different work environments. *“A lot more confidence going forward, going to work, securing work and going to different places”* (Bill: 511). He felt that having survived the ‘ultimate being death’ made him stronger, more decisive and grounded. There is a sense of achievement at having the physical and mental stamina to endure the SCA. He now used this strength and element of being grounded and self-contained to deal with other challenging aspects of his life. *“I’m actually more confident now than I was before the arrest...I survived death, therefore, I’m actually quite positive about life now. I’m actually more mentally confident in my own space”* (Bill: 519).

### **5.3c. A Changed Outlook: Deeper Connection with what is Valued**

Incorporated in this subtheme is the participants’ expression of being more aware of what was important and of value to them. This included a deeper felt sense of connection to what they considered meaningful and vital to their sense of living. This meant a sharper appreciation of needs and wants, and appreciating people and relationships, particularly family, faith and supporting others in a similar circumstance. In a sense, there was a more upfront and honest dialogue with self, indicative of having faced the starkness of reality and the fragility of life. These points are detailed below.

Many reflected on life being precious and not taking it for granted. Having feelings of appreciation and a deeper respect for life seemed commonplace for many after SCA. Teresa, having faced death suddenly and unexpectedly, expressed a gained awareness of it helping her live better. In a sense, there was some familiarity or assurance now that death would happen to her and that it could happen quickly. This gave a certainty, which enabled her to refocus her outlook on life in a timely way, assisting in fulfilling many other experiences.

*I think one of my major things is that life is very unpredictable, really, um, people do die, um, which you kind of know but now it’s been really, now I’ve really faced it, that that is what happens, um and you never really know. People can die anytime for different reasons, so I think that has helped me* (Teresa: 1332).

She also felt that if she was not enjoying something she would leave unhesitantly. The emphasis made after SCA was on appreciating and enjoying moments, which had become very special to her. A focus on meaningful time highlighted the dual aspect of losing one’s life suddenly and

therefore time being valued and precious. *“I don’t really want to waste time, really. If I’m not really enjoying somewhere, then, oh yeah, let’s go”* (Teresa: 954).

Wendy also expressed how this experience made her respect life much more. There was also a sense of value and deeper connection in having gained awareness of her mortality, in stark contrast to her not having considered death before, particularly as a young mother focused on family and ‘creating life’. *“I mean, it’s really cliché[d], but it’s made me respect life a lot more, you know, whereas before you think you kind of...you just never considered death”* (Wendy: 755). There was an expressed feeling of time being limited and wanting to make the most of life. As Wendy felt she had taken life for granted before, she now made an active effort to do things that were important to her in a timely way. This sense of limited time allowed a more considered approach to life and the way she viewed it, changing her outlook. *“Now I know life is a lot shorter than you think, so things...yeah, you take everything for granted”* (Wendy: 1149).

Linda also expressed getting things done in a timely way, achieving and using the analogy ‘seizing the day’ which, in light of SCA, helped drive her ambitious nature. This heightened focus on life being limited and needing to fulfil in the present moment what she had not done, gave Linda a sense of control and autonomy. This modified her earlier outlook. *“I suppose in a way it probably did shake my life, although like I said I went off the rails for those first two years, actually it probably did shake my life to get me to where I’ve got now in terms of my career, and like I said, seizing the day”* (Linda: 1010). Harry regained his drive to accomplish and experience aspects of life in a more timely way. He regained his fitness by focusing on this important aspect of life. There is a sense of achievement in competitive sport and exercise for Harry, giving purpose and meaning to his life. *“Exercise makes us feel...it’s a feel good factor, [it] gives us a sense of achievement, like I’ve done something, and also it actually gets me fitter, which is good for the heart”* (Harry: 167).

The feeling of having lost and regained one’s life so quickly meant for many a sense of impermanence and appreciating what they had. Some felt they no longer had the patience to waste time on what they considered trivial and unimportant. They did not want to hear mundane complaints from others, but rather focused on things that mattered to them. In this respect, life and its limited time had deeper value after their SCA. Bill expressed that by being more appreciative of life, he wanted to utilise time in a way that felt meaningful to him. There was an awareness of engaging with life now, with urgency and purpose. *“You know, it does make you*



*appreciate what you have and try not to waste it... therefore, you know, if someone is wasting my time I just shut them down” (Bill: 536).*

Nick also acknowledged this sense of impermanence and greater awareness of life being precious and needing to focus on what was important. There is an element of regained intensity for life and allowing oneself to choose what they attended to or gave time to. *“I began to realise which I had never done before what was really important and I began to lose patience very easily with people that moan, with what to me was minor rubbish” (Nick: 241).*

Harry had made sense of his SCA by focusing on what made him happier in life. At the time, ending his marriage was a step towards fulfilling what was important to him and leading a more contented life. This included going out, doing things more and enjoying life. In a sense, he had renewed his joy for life and was living it with more urgency.

*Probably one of the reasons I split up with my wife was because she was still stuck in a mundane world and I sort of wanted to move on from that after what happened... I was stuck in a rut and what happened in 2007 showed that I want to be like “let’s do things” and I feel as though that’s what I’m doing now and I’m enjoying life more (Harry: 504).*

An awareness of what was important meant that, for many participants, their attitude towards life changed. Steve expressed his change in values from an earlier life driven by material wealth. He experienced a shift in noticing, appreciating and valuing the smaller and simpler things in life, in essence not taking life for granted. In a sense, his earlier values and outlook altered where he focused on appreciating simple pleasures. This enabled him to feel happier and alive. In a way, this was a reconnection to what gave him purpose and meaning with added emphasis on avoiding triviality.

*Things that used to be important to me now I don’t give a hoot about and things that didn’t use to be important to me are now important, so all my values without a doubt, all my values have realigned (Steve: 765).*

*I have a new appreciation of really fundamental things to life like nice food and the rain and the wind, the sunshine, you know the things that a lot of us and I did...take it for granted or moan about [it] (Steve: 883).*

Some participants felt the importance of family relationships heighten. In particular, Diane, Teresa and Linda expressed this in terms of spending time with their children. There was an added emphasis on creating more experiences. This increased awareness of mortality seems to have sharpened and strengthened the mother-child bonds. In a sense, her own fear of death and increased awareness of having another arrest translated into the overly-attentive care Diane gave her daughter. This focus on increased love and care also magnified a constant preoccupation with the loss. It nevertheless, highlighted the importance of what she valued. *“I spoil her too much, I give her too much love if that’s even possible, because I’m afraid that it can happen again and she won’t have a mum”* (Diane: 695).

Teresa made sense of her relationship with her children by spending more time with them. In a sense, she has become more aware and attuned to them as individuals, becoming interested in their adult lives. There is a sharper awareness of what she valued and was important to her, which created a sense of enjoyment and purpose. She seemed to have allowed for a deeper connection with life in terms of her appreciation of what she had. This, in turn, changed her earlier outlook. There seemed an element of viewing life through a different lens, a brighter one, where she concerned herself with what was meaningful.

*I really value friendships, time that I’m spending with my kids individually. I’m really...I really value that...there’s been a change, quite a big change, almost as though it sounds a bit...almost as though everything’s in technicolour whereas before it wasn’t. Everything is sharper, my enjoyment...I wasn’t [a] misery or anything before, but my enjoyment of life on a certain level is far deeper and richer* (Teresa: 828).

There is also a sense of increased support and closeness from particular family members after SCA. Linda contemplated her relationship with her mother, which became very close after her arrest. She made sense of her SCA in terms of there being a positive gain from her experience, which was to have a closer mother-daughter bond. This enabled much support for her, giving an element of shared experience, protection and deep connection.

*I was always quite an independent person anyway, um. so in some ways I think it had a positive effect because my mum and I became closer...every time I walked out the door she’d tell me that she loved me and...because she was always worried that I would never come back through the door* (Linda: 255).

Some participants reconnected with their faith. They made a link between SCA and their religious belief system around mortality. Nick used his Jewish faith to help with his quest for answers after SCA. He eventually made sense of his survival by linking it to a miracle, rather than 'blind luck'. He found clarity in his connection to religion. *"Yeab, it was my first miracle. I think that's the best way to put it"* (Nick: 679). Teresa, having previously been an atheist, started questioning and looking into religion for answers. This created a shift in perception and openness to possibilities. In a sense, she had reconnected with a more open and curious part of herself, which enabled an element of freedom in what she considered or valued. *"I'm changing to being more agnostic, open-minded as to what could be there... I'm more open, whereas I think I was very definite before, so that to me has been quite a big change"* (Teresa: 1051).

Some participants reflected on using their own experience in supporting other survivors as well as raising awareness of SCA through the community. One way was to increase awareness of more external defibrillators being needed in public spaces like schools and shops to assist emergency services. Dave wanted to give something back to society for having survived himself. He was aware the majority of people who have SCAs do not survive, particularly if there is no individual or defibrillator available to them at the crucial time of an arrest. In a sense, a need to support others gave some meaning to his life and survival and an ability to create social change. *"A lot of people aren't as lucky and I thought, okay, that would be a good thing to do, so again a bit more of a social conscience I've developed...umm... and a need or want to sort of pay back or to help people"* (Dave: 367).

Nick became more involved in raising awareness and telling his story at public conferences. It was important for him to have his story heard, which gave him strength and autonomy to use his experience for good, helping someone else. In a sense, helping others gave him a sense of purpose, achievement, and meaning: *"That gave me such a feeling of empowerment for a time as far as I know that I could make a difference and at that time, five years after it happened, that was very very important to me"* (Nick: 516).

For some, being part of an online support group meant they could help other survivors by sharing their own stories and experiences. Steve reflected on being part of a cohesive and supportive community group. This element of connection and acceptance allowed a sharing of experience that was unique. *"It's just a group of people who've been through the same thing trying to help other people who've been through the same thing and, um, it's really nice, you get a bit of warm fuzzy feeling"* (Steve: 1064).

Linda supported other young survivors. She made sense of her own SCA at a young age in terms of what she struggled with, but also what she had achieved. It was this sense of achievement at having fulfilled many life goals that she now passed on to other young survivors, instilling hope for their future. There was a sense of finding purpose again in her own survival and at being able to share her experience, perhaps as a 'role model' for teenagers.

*It was nice actually to sit down and talk and go through her experiences and I did recall what I could of my experiences and, yeah, we've kind of kept in touch via Facebook, um, yeah, it was kind of nice, I suppose, to say, you know, that life isn't over. You know, it's a very confusing time and it is at the moment, but actually if you go on the right path and you can do what you want to do, really, so kind of...I suppose it felt like I was giving her words of wisdom maybe [laughs] (Linda: 629).*

## 6 DISCUSSION

The findings and themes show how the participants managed their situation, focusing on the quality of their experience of SCA (rather than cause and effect) in terms of symptoms of anxiety and depression. This, therefore, makes it difficult to compare these findings with those of the many existing studies, which measure the outcome of SCA in terms of symptoms, rather than a personalised account of the experience. Nevertheless, I will be discussing the findings above in reference to similarities to and differences from the existing literature. This is in keeping within the IPA framework, in which new information at this stage (when results are known) can be sourced. My discussion will commence by referring to and expanding on each superordinate theme separately. I will then review novel themes in terms of how they contribute towards new findings in the field of SCA studies.

The first superordinate theme, 'Psychological Dissonance: In the wake of SCA', is about individuals regaining consciousness and waking up to the shock and disbelief of being told of their experience. The unexpected, unique and sudden nature of SCA can render the event unreal. Similar to my findings, feelings of disbelief and bewilderment were expressed by participants in the study by Dobson et al. (1971), in which all 20 participants described uncertainty, fear, and initial anxiety. Not having a memory of the actual event, and quite often days and weeks leading up to it, allows for some a sense of space, a sort of detachment from the experience itself and the possibility of traumatic memories. Similarly, studies by Schaaf et al. (2013) and O'Reilly et al. (2004) found that emotional distress is prevalent after SCA in one in four people, particularly the development of avoidance symptoms indicating posttraumatic stress. Two of my participants, Dave and Diane, experienced further arrests while in hospital, which they remembered, and those memories were of fear and panic. Their anxieties are also reflected in their interviews where they describe managing everyday activities with apprehension.

Without a memory linked to SCA, the event seems even more unfamiliar, as participants would often try to piece together what happened in order to understand and put it in context. This gap in memory often makes the experience difficult to grasp and confusing without there being an embodied sense of having gone through it. This is similar to the Bremer et al. (2009) phenomenological study in awakening from SCA with loss of memory, sense of time and

coherence, which meant participants experienced a sense of threat, needing to piece their experience together and make sense of it.

This sense of unreality acknowledged the absurdity of how meaningless and transient life is (Sartre, 1943) and therefore one constantly needs to recreate meaning from experience. Primarily this meant my participants wanted to know more and increase their knowledge around cardiac arrest, a particular condition or diagnosis, and what caused it. Forslund et al. (2013b) conducted a phenomenological study aimed at highlighting meaning and also found a common feeling of 'having missed the whole event upon awakening', 'the realisation it was not their time to die' and 'seeking causal explanation, questioning whether life would be the same'. Looking for a reason as to why it happened and building meaning from it helped rebuild a sense of control.

In this current study, many participants did not have a direct causal link to their SCA, which created further uncertainty and fear. This meant they could not manage their lifestyle in a way that gave them some assurance over their lives and hence were susceptible to random reoccurrence. Many felt uninformed by medical staff, thereby having to gain further information and seek causal assurance from websites, support fora and family members.

The second superordinate theme is 'Existential Loss', which explores what SCA has meant in terms of what appears to have been lost or changed on a personal level. All participants recall some shift in how they viewed themselves and life after SCA, in that it represented something to all. These changes are in the form of comparing a current and former self, for whom physical restrictions, memory loss and/or emotional felt responses alter a sense of identity and reality. This awareness that, on some level, they are changed by the experience can be difficult for some participants, who feel aspects of their 'normal self' have been taken away. This can also be seen as a loss of meaning (Sartre, 1943), creating uncertainty and anxiety as to what an individual's place in the world is now.

Feeling angry and frustrated with a newly changed self is indicated in most participants' expression, particularly where physical and cognitive comparisons were made pre- and post-SCA. Participants reflect on changes or limitations to their physical health, which have restricted their work, social and practical lives. Expressions of frustration, anger, and resentment when comparing selves often related to the fear of what they held tightly and valued, but now felt removed, shifting

their sense of 'normality'. This disruption (Bury, 1982) to their self-construct meant needing to re-examine their expectations and future. Existing quantitative studies by Lundgren-Nilsson et al. (2005) and Moulaert et al. (2010) have also shown a link between difficulties in adjustment to physical health and emotional well-being when higher levels of stress, anxiety, and depression were reported.

De Vos et al. (2009) and Wachelder et al. (2009) showed individuals with pre-existing cardiac conditions experienced poorer adjustment. Similarly, my current study revealed that post-morbidity in some participants meant their emotional recovery and adjustment was a longer journey at times. For some, this meant their sense of self diminished, such as for male participants who strongly identified with their gender role and felt aspects of their masculinity had been taken away. Multiple or compound losses experienced in other areas of life and/or close family bereavement also contributed to a diminished self. Rosman et al. (2015) similarly found that half of their participants who had a traumatic exposure before SCA expressed feelings of helplessness and fear.

All participants expressed a sharper awareness of their own mortality having been close to death. For many this was the first time they had confronted this reality and considered their own deaths. This not only brought about a fear of death, but the awareness that it is not possible to avoid one's own death. This reminder changes the perception of life and reality. There is a need to manage the fear of death and another SCA whilst confronting the stark reality of an uncertain and limited life. 'It covers what is peculiar to the certainty of death, that it is possible at every moment' (Heidegger, 1962, p. 264). This can create tension and anxiety, with gratitude felt about surviving coupled with an increased concern about it reoccurring.

According to May (1983), the term 'anxiety' is defined as 'the state of the human being in the struggle against what would destroy his being' (May, 1983, p. 21). The threat stems from the core of one's personality, self-esteem, the experience of oneself as a person and feeling of being and self-worth. The threat may be to physical life: the threat of death, psychological existence, the loss of freedom and meaning, or some other value that one identifies with one's existence such as patriotism, the love of another person, success and so on (May, 1977).

Bremer et al. (2009) found the 'elusive life-threat' receded through gaining more understanding and finding meaning in their survival of SCA. Gamper et al. (2004) showed that those with more intrusive thoughts found it difficult to assimilate their recollections of SCA, resulting in an impaired quality of life. Similarly, Ketilsdottir et al. (2013) found dominant themes of anxiety and lack of security and uncertainty in the future to be major concerns. However, Larsson et al. (2014) found that when individuals perceived themselves as less anxious and depressed, their overall quality of life scores increased.

Feelings of anxiety and fear were at times commonplace in my research findings, along with a need to sometimes rationalise thoughts and avoid thinking about the SCA experience in terms of future probabilities. A feeling of being overwhelmed was described, and needing to manage this by altering their short-term focus. Trauma studies by Martin and Kleiber (2005), Tedeschi and Calhoun (2004), and Altmaier (2013) recognise that after a close brush with death individuals are likely to alter their assumptive beliefs and develop new ones, transforming changes in self-perception. A need to assimilate the new experience into their emotional and behavioural life post-SCA arises. In cognitive theoretical parlance, there is a 'cognitive restructuring' in terms of processing the experience.

Although existing studies by Schaaf et al. (2013), O'Reilly et al. (2004), and Gamper et al. (2004) suggest SCA survivors are likely to have PTSD type symptoms according to DSM-IV, but this was not found in my study. A few participants only described post-traumatic stress, in reference to their loved one who had found them or been there at the time of their arrest, and performed CPR. These individuals sought support or counselling for post-traumatic stress. Some participants themselves felt that being unconscious throughout afforded them a level of protection because there was no memory of the trauma.

Although only two participants mentioned suicidal ideation and attempts, as this was an idiographic study, I felt it was important to mention this in order to capture the uniqueness of individual participants as well as across-case IPA analysis. This theme captured the interplay and paradox between life and death. At points in their lives after SCA, they each felt major losses at a deep level, which led to them questioning their mortality. At times their survival felt overwhelming and uncontrolled as they struggled with changes to their lives, particularly physical constraints that led to changes in work, career and social relations.



There seems a contradiction between surviving near-death on one hand and contemplating ending one's life on the other. This resonates with Altmaier's (2013) theory that in psychological and physical fear, an attempt made to protect oneself by escaping is, in a sense, gaining personal control. On a surface level, this suggests an ultimate expression of self, seeking meaning and fulfilment. These participants struggled to find meaning in their lives.

Having experienced such a threat to life, most participants expressed a heightened sense of physicality. A need to focus more on the body meant monitoring their heartbeats and any sensations or changes to functioning, which included managing their ICD. Van Manen (1988) states that 'at the moment when our wellness is disturbed then we discover, as it were, our own body' (p. 7). Humphreys et al. (2015) also found an increased focus on the body, which meant participants were continuously attempting to control and protect themselves in order to regain some control. They did this by avoiding and restricting activities they felt related to device firings.

While SCA survivors do not have a cognitive memory of the event, their body knows the experience as central to their very existence. Merleau-Ponty (1962) states that 'the body expresses total existence because existence realises itself in the body' (p. 192). Feelings of insecurity and uncertainty and needing to regain a former life were amongst the concerns expressed in the study by Ketilsdottir et al. (2013).

My findings were similar to ICD studies by Sears et al. (1999) and Kamphuis et al. (2003) in terms of individuals with an ICD having a greater preoccupation with their physical health. However, for the majority, the ICD implant acts as a physical and emotional reminder as well as providing assurance as a protective element or a tool they could rely on for survival. This meant they felt less worry or anxiety over the uncertainty and unexpected nature of further possible firings.

In my current study, two participants expressed increased emotional stress because of their ICD, which centred on the uncertainty of it firing and having less trust or control in the device. Interestingly these individuals did not experience further arrests that instigated their worries, as some literature suggests (Dunbar et al., 1999; Kamphuis et al., 2003). However, as Sears et al. (1999) point out, other elements of the individual and their support system, life stressors and adjustment play a role in one's response.

Accepting a changed self and managing life with differences was stressful for some in terms of trying to keep hold of what was familiar. Many felt unsupported by family members, friends, colleagues and medical staff. This increased their sense of isolation, coming to terms with their experience on their own without validation. This was often expressed in how they felt alone with others not understanding their experience and not having someone to speak to. A lack of emotional care in terms of no counselling support being offered was often stated. Many participants felt there should be ongoing emotional support available, particularly because of their younger age, the sudden nature of SCA, long-term implications, managing a new diagnosis, treatment plan and having an ICD.

Similarly, the participants in a study by Forslund et al (2013b) expressed how important it was for them to be able to express in dialogue what happened to them, as opposed to a one-way conversation they had in the hospital. They spoke of a need to search for an explanation and to speak more with healthcare professionals in order for them to recover from or assimilate the event. Feeling ambiguous in relations was another subtheme, as well as needing to return to and revalue life. An increased awareness is clear in how survivors interpret, make meaning and assimilate their situation bound up in their social interactions (Willig, 2008). Dobson et al. (1971) also found that participants expressed a need for more information and support in hospital to be able to talk about their experience. Although my findings of 'feeling unsupported' were expressed namely in terms of particular family members, there were also situations with colleagues, friends and health professionals where they felt an acute lack of emotional care.

There was also a general sense of non-acknowledgement from society, including social services where their condition and SCA experience felt minimised, including a lack of financial support. This often resulted in a sense of alienation where their struggle to be recognised and emotional fears were compounded. This is similar to Kellehear's (1996) theory in which a survivor's environment becomes threatening and unfamiliar, increasing the chances of alienation or isolation (*ibid.*, 1996). This is perhaps indicative of the need for more information on the increased number of people surviving and living long-term after cardiac arrest, particularly those under the age of 60 without a known heart condition whose lives include the cumulative effects of SCA over time.

The third superordinate theme is 'Living in the Here and Now: Meaning Emerges'. This encompasses elements of a hopeful, positive and confident self; regaining a new sense of normality

through self-acceptance and moving on; and appreciating life and feeling grateful. On the social side, there is a deeper connection with relationships, particularly family, and helping others through similar situations. What is held dearly and valued is discussed through the importance of creating memories, closer attachment to others and reconnection to faith. This seen in reference to Van Deurzen's (2005) existential theory, which refers to the spiritual dimension of existence.

Having a changed outlook refers to seeing the world through a different lens and engaging with the world differently, in a sense a different reality. This occurs when perspective, viewpoint, and the importance of values and beliefs alter and are renegotiated after a life-threatening event. The world is never the same again, although as Sartre (1943) argues, we are not 'fixed', but constantly creating a sense of self through life experiences. These unique individual perspectives and meanings develop out of an embodied and situated relationship with the world. My participants have emerged from their experience with a unique take on the world, one that stems from an earlier history, affective response and resilience and supportive network. Many expressed feeling changed for the better in terms of regaining a new enjoyment for life, becoming more driven, confident and hopeful. In a sense, having gone through the most threatening experience to life, they are now able to confront everything else.

The majority of participants expressed a positive new outlook and gained hope, inner strength and a desire to get more out of life and drive to have valuable experiences. Qualitative studies by Forslund et al. (2013a), Forslund et al. (2013b), Bremer et al. (2009), and Ketilsdottir et al. (2013) all found the main theme amongst participants of 'having a new view or outlook on life' after their SCA experience.

Finding a new sense of normality and making sense of their experience is entrenched in a self-accepting and autonomous way, depending on how each participant takes on his or her position in life, by having created meaning out of the experience, and in a sense creating some freedom (Merleau-Ponty, 1968) in his or her efforts to move on. How they have made sense of the SCA experience and what meanings they have placed on it can influence outlook and choices (Sartre, 1943). Staying grounded and experiencing life with more focus on time being limited enables meaning to emerge out of the temporality of existence (Heidegger, 1962). This is similar to Bury's (1982) sociological theory, claiming that all major life transitions require a period of reorientation

and then integration, in which one accepts their altered social values, lifestyle, personal and cultural identity.

A 'lucky versus unlucky self' symbolises this journey of progression, in which it was felt they were lucky to have survived the SCA, but also unlucky that it happened at all. There seems to be a duality between being a minority in experiencing SCA and that of uncommonly surviving it. Integrating these thoughts into making meaning out of their experience allowed them to find the courage to live the life that one hopes for within the spectrum of uncertainty, anxiety, and uneasiness, which is always challenging. Participants' conflicting thoughts and emotions highlight patterns of how they are in the world where holding these tensions are commonplace. Similarly, Forslund et al. (2013a) found a dominant theme of 'being grateful for a second chance'. This element of chance and feeling lucky reflects their outlook looking forward, in terms of integrating a more positive and hopeful self.

Martin & Kleiber's (2005) theory argued that having faced death, individuals will have a tendency towards confidence, assertion and enhanced appreciation for the ordinary things in life with less interest in material things. In my current study, seven participants expressed an increased confidence, hope and positive attitude towards life after their SCA and were able to build strength from the experience. This confrontation with one's own death can cause individuals to reassess their plans and priorities (Yalom, 1980), and hence many participants expressed a changed perspective.

Amongst my participants, there was a deeper connection with what was valued and more awareness of what was important and meaningful to them: attuning to personal needs, appreciating close family and relationships, connecting to faith or beliefs, and helping others. Family bonds and the desire to protect loved ones were strengthened. Their sense of self, role and purpose seemed shaped by acknowledgement of their values (Strasser, 1999). Arguably, there is an openness to existence, which is more authentic in following one's own values (Heidegger, 1962).

An increased awareness of human fragility and facing death meant a sharper focus on life being limited and therefore needing to enjoy it, by having fulfilling experiences and connecting with what is valued. Having faced the possibility of one's own death and living in the here and now affords a direct and more conscious focus on what value and importance are taken from life, living

truer to one's wishes and desires. Some expressed enjoying life more and having deeper, fuller conversations and experiences, as their attitude towards life had changed, and they felt more appreciative.

This journey characterises an ontological awakening or discovery in which a renewed appreciation for living reflects gratitude at being given a second chance. This shift was in noticing and valuing the smaller and simpler things in life and not wanting to take things for granted. A sense of time and priority had shifted where life was limited and things that mattered took priority. Martin and Kleiber (2005) argue that individuals who have had a close brush with death emphasise personal values over culturally-derived ones and focus on the present. Some of my participants felt this made them less patient with people who complained about issues they felt were unimportant and 'time-wasting'. Time in this sense had deep connotations: it felt precious, and there was value in simple moments.

Some participants felt a reconnection with faith and could make sense of, or find comfort and purpose in, their belief in God or in a higher source as explaining their survival. Having a spiritual connection can form part of an individual's set of values and beliefs and help with making meaning from experience. Helping others and raising awareness of SCA was important for many who wanted to give something back. All my participants belonged to online support groups and many expressed needing to help and support other survivors and be part of a communal group sharing concerns and ideas. There was also a focus on increasing knowledge and community awareness for defibrillators, enabling others to survive. This fits with the qualitative studies mentioned, which were seeking meaning from experience in a general sense. However, my findings and subthemes on 'supporting others' and 'reconnection with faith', differ from the existing literature. This reflects the small number of qualitative studies on SCA that include personal accounts of lived experience.

My participants are managing a self that is at times hopeful, appreciative and enjoying life with added awareness of personal values and meaningful experiences. This outlook is positive and embraces a more authentic approach to life. There is also a lived sense of reality around mortality and acceptance of one's limitations, which highlights vulnerability, uncertainty, and fear. How each participant has made sense of and interpreted their experience enables them to create this balance between the possibilities and limitations of life viewed in reference to the theory of the existential

dimensions of human living (Van Deurzen & Young, 2009). There is a journey of self-discovery, having undergone the immediate impact and realisation of their SCA, recovery process, and post-experience years later.

This included an ontological reawakening in which the importance of life, what was of value to them and how they found meaning was prioritised. Their outlook on life arguably has an altered sense of reality, which now encompasses their SCA experience and sharper attunement to their lives. In terms of emotional well-being, participants in this study have shown remarkable change and a myriad of feelings and expressions during their reflective process and journey. Some of these are highlighted in existing studies, particularly in the qualitative research and perhaps indirectly in the quantitative research under the quality of life bracket. This reflects the varied results in emotionality often reported, not only due to the heterogeneity of methodology, but also suggests the uniqueness of the phenomenon of SCA. Life after clinical death potentially affects many areas of a particular individual's subjective life.

## **6.1 New Findings**

This current research has strengthened the findings of previous studies, particularly quantitative studies and its themes around symptomologies of anxiety, depression and increased stress (due to fear of mortality and ICD). In qualitative studies, similar themes have included confusion around memory gaps, seeking causal explanations, sharper awareness of own mortality and fear of death, uncertainty and anxiety at striving for a former life, restricting behaviours and redefining goals, and making meaning in life. These studies, however, have tended to focus on in-patient hospital care, with older participants with pre-morbidity often having had a heart attack as a precursor to their SCA. The majority of studies (particularly qualitative) have also captured survivors with considerably shorter post-arrest periods.

My research has a different focus. Firstly, it has focused on the emotional impact and well-being of survivors over time, integrating a holistic or integrative exploration of the lived person. How survivors experience outlook on life, what is valued and important to them and their sense of emotional well-being is critical (and novel) to this investigation. Secondly, it considers a younger population (under 60) without a pre-existing heart condition, in an attempt to capture what the sudden and unexpected SCA experience has been like in otherwise healthy young individuals.

Thirdly, capturing individual experience with a minimum of 2 years post-arrest time has allowed for considerable reflection time. The variability in this study of between 2 and 20 years post-arrest time has not been a theoretical comparison with other survivors at similar stages, but rather how individuals have made sense of experience at various stages of their lives. Fourthly, using a novel methodology of IPA (not seen in previous SCA studies) has enabled a psychological research method grounded in phenomenology, hermeneutics, idiography and existential ideas. This allows for a rich account of lived experience.

The novel themes found included (A) the ‘shock and detachment at their SCA seeming unreal’. This highlighted the importance of initial impact and waking up to a new discovery, having survived a completely unexpected and sudden threat to their lives. This can create confusion, fear and uncertainty for many who find themselves in hospital needing to make sense of what happened. Some faced new diagnoses, limited physical capabilities, memory loss and emotional upheaval. It is a significant time for survivors to be offered emotional support, if needed, together with their physical recoveries.

Another theme found was (B) ‘the self (identity) being diminished and causing resentment, anger and suicidal tendencies’. This showed how survivors felt impacted by the sudden changes experienced after SCA. They viewed themselves differently and in many cases found it difficult to incorporate where it affected many areas of their lives, including family, home life, relationships, work and social life. Many felt isolated at having to reintegrate back into life and their responsibilities (particularly being a younger working age) without emotional support. The importance of recognising and validating those who have had a SCA seems particularly evident in those struggling with their physical and emotional health. Financial concerns and social restrictions can also affect a sense of well-being.

The theme (C) is ‘a heightened sense of focusing on their bodies in order to control or self-protect’. This highlighted the importance of the effect that being overly-concentrated on their bodies has on their emotional health. At times stress, fear, anxiety (resulting in limiting their activities) is experienced. This is usually a result of their constant checking of heartbeat and ICD. This also has an impact on social life, sports, exercise, travel and career, highlighting important elements of survivor transition and post-care being necessary to reintegrate into life.

Theme (D) 'minimal emotional support from medical staff, family and friends' shows the enormity of experiencing SCA and how invisible many feel without support to help them transition back into family, work and social life with a heightened sense of living and fear of loss. Many felt unacknowledged by and isolated from family, friends, colleagues and medical staff who offered little in terms of understanding their emotional experience and offering support.

Theme (E) 'making sense of experience through the balance of being lucky versus unlucky' shows how many made sense of what happened, enabling some meaning to be made. This is important for survivor well-being in finding a balance between having it happen to them unexpectedly for no fathomable reason versus being in the few who have survived, which might increase a sense of gratitude. This followed theme (F) 'a deeper connection with values, including a regained appreciation for life, added awareness of limited time and focusing on what was important like family, spirituality and helping other survivors'. These are significant in terms of recognising survivor journeys and how making meaning from SCA has enabled a more balanced and sharper focus on their lives. It is equally important to note this continual balance in their lives (rather than one or the other) of increased fear and uncertainty over appreciation and deeper connection with life.

Lastly, theme (G) 'a changed outlook supported a more hopeful and positive self' is indicative of having survived the worst challenge and now being stronger (and more aware of their strengths). This important reflection of confidence shows how many have been able to find meaning and purpose through their difficult experience. These positive and growth elements are particularly relevant to them gaining a sense of autonomy and integrating the experience. It also shows how balancing the possibilities and limitations of life is a constant exercise, which seems particularly urgent in those who have survived a sudden brush with death. Participants show a heightened focus on existential themes around life, death, survival (freedom), isolation and meaninglessness. These are important to incorporate when working towards integration, acceptance, transition and meaning in their post-recovery journeys. Focusing on individual outlook and emotional well-being provides a contextual setting in order to incorporate all these crucial facets of human development and experience.



## 7 CLINICAL IMPLICATIONS

A counselling psychologist or psychotherapist who has worked with bereavement and loss and/or people with physical illnesses may provide a needed initial connection for survivors. An understanding of the complex and unique nature of SCA is necessary, as well as an appreciation for working experientially. This work involves understanding a person's experience and story and allowing this process of facilitation to enable the survivor client to gain more insight, awareness, autonomy and eventual growth. An opening up and exploration of experience including feelings, thoughts and emotions and its effect on different areas of life is important here, rather than focusing on removing or minimising negatively felt ones. The premise is that there is value and importance in the wide spectrum of emotionality and a need to understand and explore this at length. There is an opportunity for survivors to better understand and manage their emotional health by making sense of life through recovery from SCA and its implications.

Helping to support a survivor's early transition after SCA means allowing them to process their thoughts and make sense of potentially overwhelming fears or concerns. This is done in order to manage their lives going forward, with a better understanding of their emotional health, and having validation and support, rather than feeling alone, isolated and unfavourably different. As anxiety and struggle are usually what makes a person question their own life, they can also be the deciding factor in entering some form of therapy. The importance lies in how this is experienced and how in a relationship one can begin to make sense of the experience from different angles and from different perspectives, allowing more growth and possibility.

The results of this study revealed some potential issues, which counselling may address. I will propose how an existential phenomenological model could work with a few of these, namely a fear of death, otherwise known as death anxiety, and the importance of finding value and meaning in life. I will focus on these in terms of what survivor clients may present within a clinical setting.

Most participants expressed more fear relating to their mortality and facing squarely the realisation of their own deaths. This precipitated concern and worry over their lives and a greater emphasis on monitoring physical health and the environment. This was characterised in their anxieties around surviving, having another SCA, which could be fatal, and living day-to-day with more uncertainty. This is particularly salient when an awareness of the fragility of their lives is in

constant flux. Yalom (1980) argued that this is rarely in its original stark form, but rather displaced, and that 'death anxiety' is expressed as fear. Working therapeutically with death anxiety and the fear of loss is deeply rooted in how an individual makes sense of their life experience. SCA survivors being able to express their thoughts and feelings on their mortality and talk through their concerns and fears in a supportive environment may be invaluable.

Using the personal, physical, social and spiritual dimensions framework of existence (Van Deurzen, 2005) would help integrate how an individual sits with death anxiety, including moving across dimensions to explore lived experience and what meaning and interpretation can be made. The way in which a person orients themselves in the world and what attitude they take at any stage shows through the four dimensions of human existence. This unique way of encountering life makes up each person's reality.

As death anxiety attacks the secure base of an individual, their core values and personality are under threat (May, 1983). SCA survivors experience sudden vulnerability in which what they may have taken for granted has become uncertain and therefore life may seem absurd or insignificant, leading to questioning all that was held dear: the stark paradoxical reality of life faced, rather than the more negative aspects of human existence denied. Living authentically starts with recognition of one's personal vulnerability, including mortality, and with the acknowledgement of the ultimate uncertainty of everything.

Therapists help to examine a client's assumptions in order to shed light on and expand their beliefs, values, and aspirations. Having an honest dialogue helps to widen perspective so that they find clarity in what is valuable and meaningful in their lives. Making fears explicit enables clients to question their beliefs and approach ideas with new awareness. This may open up new ways of perceiving a client's story by looking at and challenging contradictions. Attending to conflicting thoughts and emotions may highlight patterns of being in the world from both a personal and a more objective, relational viewpoint. A therapist, being able to suspend their assumptions, is more open to witnessing phenomena in a purer form without jumping to interpretations or conclusions.

Importantly, being open to the possibilities and limitations of life enables a more balanced approach. In facing death and its ensuing anxieties there is also the authenticity of facing life with heightened consciousness. For example, from understanding past experiences, a meaningful and

important future path can be created. In this sense, a therapist helps recognise an individual's existential anxiety and finds ways to live with it constructively, rather than in denial. This can be in terms of finding pleasure, comfort, purpose and a renewed sense of meaning and responsibility in their lives through goals, personal connections, relationships, activities, and career aspirations. Owning one's place in the world and having a level of trust, belief and value in one's own thoughts and emotions will also inevitably involve uncovering and holding the uneasiness and tensions of everyday life. A full engagement with life also implies a level of self-trust and openness in facing one's 'potential for being', with those ontological concerns of existence around finality and death.

The values and principles individuals hold (and examining those) offers clarity as to what is important and what makes life worth living, particularly what meanings they place on people, objects, and any tensions that may exist. The givens and paradoxes of life are considered, including death, freedom, isolation and meaning (Yalom, 1980). Finding a sense of direction and purpose after experiencing SCA may enable survivors to regain a sense of having choice and autonomy. Exploring possible opportunities and challenges may help to restore a sense of normality and hope. Enabling a person to be aware of, and able to incorporate, the paradoxes of life allows more truthful living, as opposed to suppression. The aim here is to help guide a person through these life changes with more reflection on what is achievable, desired, attempted, lost and unachievable.

A therapist needs to be aware of this journey and facilitate concerns over loss and death with a reprioritization of goals. The importance of finding value and meaning for survivors is entrenched in them being able to assimilate the experience and take something from it to support their future growth. This could be insights into further understanding what is most important to them and a sense of moving through their SCA with more renewed focus on their lives. This is an exploration of living incorporating a pre- and a post-SCA account of experience bound in one's individuality, culture and historical period. This allows a person to gain a sense of perspective on their lives.

Frankl (1988) emphasised that even tragic and negative aspects of life, such as unavoidable suffering, can become a human achievement by the attitude a person adopts towards their predicament. Awakening experiences, such as a near-death event or illness, can act as a catalyst for one's own death anxiety. It is through some of the life-changing painful events that one comes closer to the realisation that life is limited. What perception of mortality one has can have significant consequences for how one chooses to live and think about their life.

## 8 CONCLUSION

This phenomenological study has contributed to the small amount of existing literature on emotional well-being. It has highlighted novel and important themes: shock and detachment at the un-reality of SCA; the self (identity) diminished and causing resentment, anger and suicidal tendencies; a heightened sense of focusing on their bodies in order to control or self-protect; and minimal emotional support from medical staff, family and friends. It also included making sense of experience through feeling fortunate; a deeper connection with values, including regaining an appreciation for life, added awareness of limited time and focusing on what was important such as family, spirituality and helping other survivors; and a changed outlook supported a more hopeful and positive self.

Exploring outlook is important because it can tell us where a person is in regards to their attitudes, beliefs and perception of life. The meaning and interpretation of life creates a certain worldview, which in turn affects health and well-being. SCA survivors are susceptible to further arrests and need to address their stressors to prevent negatively affecting arrhythmias and ICDs. Emotional well-being is an important aspect for many survivors, who need to manage their recovery and long-term physical and emotional changes.

The phenomenon of SCA is unique and potentially life-changing, affecting most people in many different areas of their lives. Therefore, once their physical health restores itself, they need to rebuild their lives. This changed outlook and the ensuing emotions and feelings can seem unfamiliar and overwhelming. One's sense of self has altered, creating a new experience, which they must learn to manage. Many participants expressed a lack of emotional support being available to them, not having an outlet to talk to someone, and feeling alone throughout this rare experience.

It is important for counselling psychologists and mental health professionals to gain more information about this phenomenon, which is affecting more people, particularly younger people and those without a previous diagnosis. There has been more publicity around SCA in recent years as a number of athletes have arrested, some of whom unfortunately lost their lives. It has also raised awareness of the need for more defibrillators in public spaces as the 'cardiac arrest state' is becoming more recognised for the unique, sudden and most threatening state to life it presents.

Survival of SCA is uncommon, although increasing thanks to greater community awareness. This also highlights the need for survivors to obtain emotional support throughout their recovery process as they regain their lives, and for the provision of additional support to manage this experience, possible new diagnoses, ongoing treatment and the effects on physical, personal, social and spiritual health.

Mental health professionals can aid individuals who may need support in regaining a sense of normality and well-being in their lives. Talking to someone through counselling or psychotherapy can enable thoughts, feelings, responses, moods and stressors to be expressed and worked through in a supportive environment. The focus is on facilitating growth and autonomy by way of staying close to their values. Family and friends support many participants, but this can mean that individual struggles sometimes ensue where each person, protecting another, may not want to express that they are ill at ease. Younger participants are also managing careers, young children and family life with the long-term prospect of managing a new diagnosis. This has clinical relevance to individual future health as well as the family unit.

Moreover, SCA survivors may be without physical diagnosis and not need regular treatment, which means they go on with life on their own without any emotional support. This can be challenging for those who have to come to terms having had SCA alone. This is why more information on individual experience is needed. This is in line with others working with physical illnesses, SCA and near-death situations, and psychosocial effects of fear, stress, and ambivalence versus hope and gratitude.

I have aimed to incorporate individual stories, accounts and reflections on the experience in this study. If we are to understand what it is like to have an experience, then we need to know what it has meant for the person experiencing it. Human experience is not so clear-cut that eliminating variables based on cause and effect gives total certainty as to what it is: there are simply too many variables, as seen in many previous studies. This study has endeavoured to describe, explore and interpret lived experience. For further studies, SCA populations could include those from non-online support groups to gain differences in perspectives and social and communal support viewed. The use of focus groups may provide another take on outlook and emotional well-being, captured between and across people as they also relate to peers.

## 9 APPENDICES

### Appendix A: Ethical Clearance

Middlesex University, Department of Psychology

#### REQUEST FOR ETHICAL APPROVAL (STUDENT)

**Applicant (specify):** UG PG (Module: ...DCPsych...) PhD

**Date submitted:** 09.10.13 .....

<b>Research area (please circle)</b>				
Clinical	Cognition + Emotion	Developmental	Forensic	Health
Occupational	Psychophysiological	Social	Sport + Exercise	
Other _Counselling Psychology_____			<b>Sensitive Topic</b> <input type="checkbox"/>	
<b>Methodology:</b>				
Empirical/Experimental	Questionnaire-based	<u>Qualitative</u>	Other _____	
<p><b>No study may proceed until this form has been signed by an authorised person indicating that ethical approval has been granted.</b> For collaborative research with another institution, ethical approval must be obtained from all institutions involved.</p> <p>This form should be accompanied by any other relevant materials (e.g. questionnaire to be employed, letters to participants/institutions, advertisements or recruiting materials, information and debriefing sheet for participants<sup>1</sup>, consent form<sup>2</sup>, including approval by collaborating institutions).</p>				
<ul style="list-style-type: none"> <li>Is this the first submission of the proposed study? <u>Yes</u>/No</li> <li>Is this an amended proposal (resubmission)? Yes/<u>No</u> <b>Psychology Office: If YES, please send this back to the original referee</b></li> <li>Is this an urgent application? (<u>To be answered by Staff/Supervisor only</u>)<sup>4</sup> Yes/<u>No</u></li> </ul> <p style="text-align: right;">Supervisor to initial here _____</p>				
<u>Name(s) of investigator</u> Tania D'Aloia				

<sup>4</sup> See Guidelines on MyUnihub

Name of Supervisor (s) Dr Chloe Paidoussis Mitchell and Dr Werner Kierski			
The title of Study: An Interpretive Phenomenological Analysis into outlook and emotional well-being of adult individuals who live years after surviving sudden cardiac arrest.			
Results of Application:			
<b>REVIEWER – please tick and provide comments in section 5:</b>			
<b>APPROVED</b>	<b>APPROVED SUBJECT TO AMENDMENTS</b>	<b>APPROVED SUBJECT TO RECEIPT OF LETTERS</b>	<b>NOT APPROVED</b>

## SECTION 1

1. Please attach a brief description of the nature and purpose of the study, including details of the procedure to be employed. Identify the ethical issues involved, particularly in relation to the treatment/experiences of participants, session length, procedures, stimuli, responses, data collection, and the storage and reporting of data.	
<b>SEE ATTACHED PROJECT PROPOSAL</b>	
2. Could any of these procedures result in any adverse reactions? <span style="float: right;">YES <input checked="" type="radio"/> NO <input type="radio"/></span> If “yes”, what precautionary steps are to be taken? Speaking to potential participants on the phone to see if there is a vulnerability. Debriefing, checking on participants and providing other sources of support like counselling services. Please see section ‘Ethics Considerations’ in the proposal where this is discussed at greater length.	
3. Will any form of deception be involved that raises ethical issues? <span style="float: right;">YES <input type="radio"/> NO <input checked="" type="radio"/></span>  <i>(Most studies in psychology involve mild deception insofar as participants are unaware of the experimental hypotheses being tested. Deception becomes unethical if participants are likely to feel angry, humiliated or otherwise distressed when the deception is revealed to them).</i>  <u>Note:</u> if this work uses existing records/archives and does not require participation per se, tick here ..... and go to question 10. (Ensure that your data handling complies with the Data Protection Act).	
4. If participants other than Middlesex University students are to be involved, where do you intend to recruit them? <i>(A full risk assessment <u>must</u> be conducted for any work undertaken off university premises)<sup>6</sup></i>  LinkedIn, BPS websites, flyers on noticeboards in a local gym, the local paper, universities, coffee shops,	

through friends' workplaces.	
5a. Does the study involve:	
Clinical populations	YES/NO <input checked="" type="radio"/>
Children (under 16 years)	YES/NO <input checked="" type="radio"/>
Vulnerable adults such as individuals with mental or physical health problems, prisoners, vulnerable elderly, young offenders?	YES/NO <input checked="" type="radio"/>
Political, ethnic or religious groups/minorities?	YES/NO <input checked="" type="radio"/>
Sexually explicit material / issues relating to sexuality	YES/NO <input checked="" type="radio"/>
Please refer to 'Criteria for participant inclusion' in proposal	
5b. If the study involves any of the above, the researcher may need CRB (police check) <input checked="" type="radio"/> YES/NO	
Staff and PG students are expected to have CRB – please tick	
UG students are advised that institutions may require them to have CRB please confirm that you are aware of this by ticking here	
6. How, and from whom (e.g. from parents, from participants via signature) will informed consent be obtained? ( <i>See consent guidelines<sup>2</sup>; note special considerations for some questionnaire research</i> ) From participants	
7. Will you inform participants of their right to withdraw from the research at any time, without penalty? ( <i>see consent guidelines<sup>2</sup></i> ) <input checked="" type="radio"/> YES/NO	
8. Will you provide a full debriefing at the end of the data collection phase? ( <i>see debriefing guidelines<sup>3</sup></i> ) See debriefing Sheet <input checked="" type="radio"/> YES/NO	
9. Will you be available to discuss the study with participants, if necessary, to monitor any negative effects or misconceptions? <input checked="" type="radio"/> YES/NO  If "no", how do you propose to deal with any potential problems? Advice by providing my contact number on information sheet	
10. Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will confidentiality be guaranteed? ( <i>see confidentiality guidelines<sup>5</sup></i> ) <input checked="" type="radio"/> YES/NO  If "yes" how will this be assured ( <i>see<sup>5</sup></i> ) Anonymizing data Discussing possible publication with participants on consent form	



<p>If “no”, how will participants be warned? (<i>see</i><sup>5</sup>)</p> <p><i>(NB: You are not at liberty to publish material taken from your work with individuals without the prior agreement of those individuals).</i></p>	
<p>11. Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere in this form?</p> <p>If “yes” please specify:</p>	<p>YES/NO</p>
<p>12. Is this research or part of it going to be conducted in a language other than English?</p>	<p>YES/NO</p>
<p>If YES – Do you confirm that all documents and materials are enclosed here both in English and the other language and that each one is an accurate translation of the other?</p>	<p>YES/NO</p>

**(NB: If “yes” has been responded to any of questions 2, 3, 5, 11, 12 or “no” to any of questions 7-10, a full explanation of the reason should be provided – if necessary, on a separate sheet submitted with this form).**

**SECTION 2 (to be completed by all applicants – please tick as appropriate)**

	YES	NO
13. Some or all of this research is to be conducted away from Middlesex University	<input checked="" type="checkbox"/>	<input type="checkbox"/>
If “yes” tick here to confirm that a Risk Assessment form has been submitted	<input checked="" type="checkbox"/>	<input type="checkbox"/>
14. I am aware that any modifications to the design or method of this proposal will require me to submit a new application for ethical approval	<input checked="" type="checkbox"/>	<input type="checkbox"/>
15. I am aware that I need to keep all the materials/documents relating to this study (e.g. consent forms, filled questionnaires, etc) until completion of my degree / publication (as advised)	<input checked="" type="checkbox"/>	<input type="checkbox"/>
16. I have read the British Psychological Society’s <i>Ethical Principles for Conducting Research with Human participants</i> <sup>4</sup> and believe this proposal to conform with them.	<input checked="" type="checkbox"/>	<input type="checkbox"/>

**SECTION 3 (to be completed by academic staff -- for student approval, go to Section 4)**

Researcher  date ...09.10.2013

Signatures of approval: Ethics Panel ..... date .....  
(signed pending approval of Risk Assessment form)

*PSY OFFICE received*  
date:.....  
date:.....

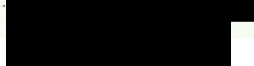
If any of the following is required and not available when submitting this form, the Ethics Panel Reviewer will need to see them once they are received and before the start of data collection – please enclose with this form when they become available:

- letter of acceptance from other institution
- any other relevant document (e.g., ethical approval from other institution):\_\_\_\_\_

Required documents seen by Ethics Panel ..... date .....

*PSY OFFICE received*  
date:.....

**SECTION 4 (to be completed by student applicants and supervisors)**

Researcher (student signature)  date  
...09.10.2013

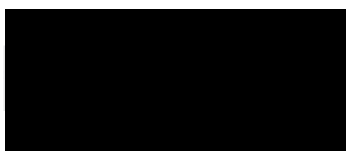
**CHECKLIST FOR SUPERVISOR – please tick as appropriate**

	YES	NO
1. Is the UG/PG module specified?	X	<input type="checkbox"/>

2. If it is a resubmission, has this been specified and the original form enclosed here?		X
3. Is the name(s) of student/researcher(s) specified?	X	
4. Is the name(s) of supervisor specified?	X	
5. Is the consent form attached?	X	
6. Are debriefing procedures specified? If appropriate, debriefing sheet enclosed – appropriate style?	X	
7. Is an information sheet for participants enclosed? appropriate style?	X	
8. Does the information sheet contain contact details for the researcher and supervisor?	X	
9. Is the information sheet sufficiently informative about the study?	X	
10. Has Section 2 been completed by the researcher on the ethics form?	X	
11. Any parts of the study to be conducted outside the university? If so a Risk Assessment form must be attached – Is it?	X	
12. Any parts of the study to be conducted on another institution's premises? If so a letter of acceptance by the institution must be obtained - Letters of acceptance by all external institutions are attached.	x	
13. Letter(s) of acceptance from external institutions have been requested and will be submitted to the PSY office ASAP.		X
14. Has the student signed the form? If physical or electronic signatures are not available, an email endorsing the application must be attached.	X	
15. Is the proposal sufficiently informative about the study?	X	

**PSY OFFICE**  
**received**

Signatures of approval: Supervisor:  
date:.....



date: 09/10/2013

date:.....

Ethics Panel: ..... date: .....

date:.....

(signed pending approval of Risk Assessment form)

If any of the following is required and not available when submitting this form, the Ethics Panel Reviewer will need to see them once they are received – please enclose with this form when they become available:

- letter of acceptance from other institution

- any other relevant document (e.g. ethical approval from other institution): \_\_\_\_\_

Required documents seen by Ethics Panel: ..... date: .....  
 date:.....

**SECTION 4 (to be completed by the Psychology Ethics panel reviewers)**

		<b>Recommendations/comments</b>
1. Is UG/PG module specified?		
2. If it is a resubmission, has this been specified and the original form enclosed here?		
3. Is the name(s) of student/ researcher(s) specified? If physical or electronic signatures are not available, has an email endorsing the application been attached?		
4. Is the name(s) of supervisor specified? If physical or electronic signatures are not available, has an email endorsing the application been attached?		
5. Is the consent form attached?		
6. Are debriefing procedures specified? If appropriate, is the debriefing sheet attached? Is this sufficiently informative?		
7. Is an information sheet for participants attached?		
8. Does the information sheet contain contact details for the researcher?		
9. Is the information sheet sufficiently informative about the study? Appropriate style?		
10. Has Section 2 (points 12-15) been ticked by the researcher on the ethics form?		
11. Any parts of the study to be conducted outside the university? If so a fully completed Risk Assessment form must be attached – is it?		
12. If any parts of the study are conducted at another institution/s premises, a letter of agreement by the institution/s must be produced. Are letter/s of acceptance by all external institution/s attached?		
13. Letter/s of acceptance by external institution/s has/have been requested.		
14. Has the applicant signed? If physical or electronic signatures are not available, an email endorsing the application must be attached.		
15. Is the proposal sufficiently informative about the study? Any clarity issues?		

16. Is anyone likely to be disadvantaged or harmed?		
17. If deception, protracted testing or sensitive aspects are involved, do the benefits of the study outweigh these undesirable aspects?		
18. Is this research raising any conflict of interest concerns?		

## Appendix B: Risk Assessment

### INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

*This proforma is applicable to, and must be completed in advance for, the following field/location work situations:*

1. All field/location work undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
2. All field/location work undertaken by postgraduate students. Supervisors to complete with student(s).
3. Field/location work undertaken by research students. Student to complete with supervisor.
4. Field/location work/visits by research staff. Researcher to complete with Research Centre Head.
5. Essential information for students travelling abroad can be found on [www.fco.gov.uk](http://www.fco.gov.uk)

#### 6. FIELD/LOCATION WORK DETAILS

**Name** ...Tania  
D'Aloia.....

**Student No**  
**Research Centre (staff**  
**only).....**

**Supervisor** ...Dr. Chloe Paidoussis  
Mitchell .....

**Degree**  
**course** ...DCPsych.....

Telephone numbers and name of next  
of kin who may be contacted in the  
event of an accident

#### NEXT OF KIN

**Name** ...

**Phone** ...

**Physical or psychological**  
**limitations to carrying out the**  
**proposed field/location work**

...Not applicable.....

**Any health problems (full details)**  
Which may be relevant to proposed  
field/location work activity in case of  
emergencies.

...Not applicable.....

**Locality (Country and Region)**

...England, London.....

**Travel Arrangements**

...Train.....

NB: Comprehensive travel and  
health insurance must always be  
obtained for independent overseas  
field/location work.

**Dates of Travel and Field/location**  
**work**

...Winter/Spring 2014.....

## 7. PLEASE READ THE FOLLOWING INFORMATION VERY CAREFULLY

### 8. Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed (**Col. 1**). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (**Col. 2**).

#### **Examples of Potential Hazards :**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socioeconomic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to the task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

**If no hazard can be identified beyond those of everyday life, enter 'NONE'.**

1. LOCALITY/ROUTE	2. POTENTIAL HAZARDS
Travel to participants using public transport namely train. The address is the Waterloo Therapy Rooms, 117 Waterloo Road, London, SE1 8UL. There will be people in the building at the time of the interviews. I will also be travelling to an office space/home location amenable to participants outside of London.	None, apart from everyday life hazard.  Pre-screening telephone conversation before the interview for risk assessment.

9. *The University Field/location work code of Practice booklet provides practical advice that should be followed in planning and conducting field/location work.*

10.

### 11. Risk Minimisation/Control Measures

**PLEASE READ VERY**

## CAREFULLY

For each hazard identified (**Col 2**), list the precautions/control measures in place or that will be taken (**Col 3**) to **"reduce the risk to acceptable levels"**, and the safety equipment (**Col 5**) that will be employed.

Assuming the safety precautions/control methods that will be adopted (**Col. 3**), categorise the field/location work risk for each location/route as negligible, low, moderate or high (**Col. 4**).

**Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.**

**An acceptable level of risk is:** a risk which can be safely controlled by the person taking part in the activity using the precautions and control measures noted including the necessary instructions, information, and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

### **Examples of control measures/precautions:**

Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances, and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

**Examples of Safety Equipment:** Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

3. PRECAUTIONS/CONTROL MEASURES	4. RISK ASSESSMENT (low, moderate, high)	5. SAFETY/EQUIPMENT
Let my next of kin know by phone, before and after I have left the location that, I am fine.	Low	I will be appropriately dressed for public location and the public building where there will be other people, therefore, following health & safety.

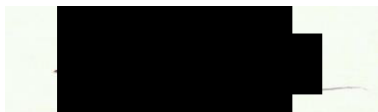


## PLEASE READ THE FOLLOWING INFORMATION AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

***NB: Risk should be constantly reassessed during the field/location work period and additional precautions were taken or field/location work discontinued if the risk is seen to be unacceptable.***

Signature of Field/location  
worker (Student/Staff)



Date 09/10/2013

Signature of Student Supervisor



Date 09/10/2013

### APPROVAL: (ONE ONLY)

Signature of  
Director of Programmes  
(undergraduate students only)

.....  
...

Date .....

Signature of Research Degree  
Co-ordinator or  
Director of Programmes  
(Postgraduate)

.....  
...

Date .....

Signature of Research Centre  
Head (for staff field/location  
workers)

.....  
...

Date .....

## 12.

### 13. FIELD/LOCATION WORK CHECK LIST

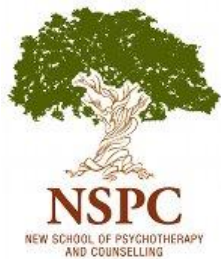
1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
  - ☐ Safety knowledge and training?
  - ☐ Awareness of cultural, social and political differences?
  - ☐ Physical and psychological fitness and disease immunity, protection and awareness?
  - ☐ Personal clothing and safety equipment?
  - ☐ Suitability of field/location workers to proposed tasks?
2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to:

- ☐ Visa, permits?
- ☐ Legal access to sites and/or persons?
- ☐ Political or military sensitivity of the proposed topic, its method or location?
- ☐ Weather conditions, tide times and ranges?
- ☐ Vaccinations and other health precautions?
- ☐ Civil unrest and terrorism?
- ✓ Arrival times after journeys?
- ☐ Safety equipment and protective clothing?
- ☐ Financial and insurance implications?
- ☐ Crime risk?
- ✓ Health insurance arrangements?
- ✓ Emergency procedures?
- ✓ Transport use?
- ☐ Travel and accommodation arrangements?

**Important information for retaining evidence of completed risk assessments:**

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating in the field course/work. In addition, the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

## Appendix C: Participant Information Sheet



An Interpretive Phenomenological Analysis into outlook and emotional well-being of adult individuals who live years after surviving sudden cardiac arrest  
being carried out by  
Tania D'Aloia  
as a requirement for a DCPsych  
from NSPC and Middlesex University



NSPC Ltd  
258 Belsize Road  
London NW6 4BT

Middlesex University  
The Burroughs  
London NW4 4BT

### Participant Information Sheet

Dated:

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if anything is not clear or if you would like more information. Take your time to decide whether you wish to take part.

#### 1. What is the purpose of the research?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University. Surviving a close brush with death for many people can be life altering. Research suggests that surviving sudden death can affect how we engage with, emotionally attune and experience our life afterwards. There has been no study into 'outlook of life' in survivors of sudden cardiac arrest without prior illness. By understanding the outlook of life in terms of the psychological effects on someone's well-being years later may enable psychologists and psychotherapists to use it to make their work more effective and that could increase the positive impact of therapy for clients. My study is designed to understand better what effects does having a sudden cardiac arrest have on the outlook in later life. You are being asked to participate because you have replied to my advertisement for people aged between 30-60 years old who have survived sudden cardiac arrest, at least 2 years on.

#### 2. What will happen to me if I take part?

I would like to interview you on one occasion for up to one and a half hours, which will be at your convenience and conducted in person either at the Waterloo Therapy Rooms, 117 Waterloo Road, London, SE1 8UL or at a space amenable to your geographic location in the UK or via Skype Video. During this interview, I will be asking you questions about your experience. I will use the qualitative research method, 'interpretative phenomenological

analysis', to extract the main themes of what you and other people tell me about their experience of surviving sudden cardiac arrest.

3. What will you do with the information that I provide?

The interview will be transcribed by me and I will not use your first or last name in the interview. I will be recording the interview on a digital or video recorder and will transfer the files to an encrypted USB stick for storage, deleting the files from the recorder. All of the information that you provide me will be identified only with a project code and stored either on the encrypted USB stick or in a locked filing cabinet. I will keep the key that links your details with the project code in a locked filing cabinet. The information will be kept at least until 6 months after I graduate and will be treated as confidential. If my research is published, I will make sure that neither your name nor other identifying details are used. You will have access to any publications arising from the study.

Data will be stored according to the Data Protection Act and the Freedom of Information Act.

4. What are the possible disadvantages of taking part?

In the interview, I shall be asking you about your experience of sudden cardiac arrest. Talking about personal experiences may be distressing for some people. If so, please let me know, and if you wish, I will stop the interview. Although this is very unlikely, should you tell me something that I am required by law to pass on to a third person I will have to do so. Otherwise whatever you tell me will be confidential.

5. What are the possible benefits of taking part?

We do not know the effects of sudden cardiac arrest on the outlook in life, but it is possible that it will be helpful for psychotherapy clients who have this experience in the future. Being interviewed about your experience of sudden cardiac arrest has no direct benefit, although some people may find it an opportunity to reflect on their experience, and could find this beneficial.

6. Consent

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached consent form before the study begins.

Participation in this research is voluntary. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without giving a reason.

7. Who is organising and funding the research?

This study is fully self-funded.

8. Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study

9. Expenses

Unfortunately, travel costs will not be reimbursed.

Thank you for reading this information sheet.

If you have any further questions, you can contact me at:

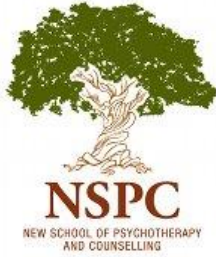
Tania D'Aloia  
NSPC, 258 Belsize Road, London NW6 4BT  
[TD240@live.mdx.ac.uk](mailto:TD240@live.mdx.ac.uk)

If you any concerns about the conduct of the study, you may contact my supervisor:  
Dr Chloe Paidoussis Mitchell  
NSPC, 258 Belsize Road, London NW6 4BT  
[ma@nspc.org.uk](mailto:ma@nspc.org.uk)

Or

The Principal  
NSPC Ltd. 258 Belsize Road  
London NW6 4BT  
[admin@nspc.org.uk](mailto:admin@nspc.org.uk)  
0044 (0) 20 7624 0471

## Appendix D: Consent Form



An Interpretive Phenomenological Analysis into outlook and emotional well-being of adult individuals who live years after surviving sudden cardiac arrest  
being carried out by  
Tania D'Aloia  
as a requirement for a DCPsych  
from NSPC and Middlesex University



NSPC Ltd  
258 Belsize Road  
London NW6 4BT

Middlesex University  
The Burroughs  
London NW4 4BT

### Written Informed Consent

An Interpretive Phenomenological Analysis into outlook and emotional well-being of adult individuals who live years after surviving sudden cardiac arrest. 2013

Researcher: Tania D'Aloia \_\_\_\_\_

Supervisor: \_Dr. Chloe Paidoussis Mitchell\_\_\_\_\_

I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

I have been given contact details for the researcher in the information sheet.

I understand that my participation is entirely voluntary. The data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so.

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

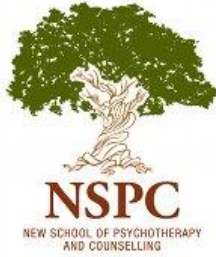
\_\_\_\_\_  
Print name

\_\_\_\_\_  
Sign Name

Date: \_\_\_\_\_

**To the participants:** Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Social Sciences Ethics committee of Middlesex University if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: \_\_\_\_\_

## Appendix E: De-Briefing Form



An Interpretive Phenomenological Analysis into outlook and emotional wellbeing of adult individuals who live years after surviving sudden cardiac arrest  
being carried out by  
Tania D'Aloia  
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from NSPC and Middlesex University



NSPC Ltd  
258 Belsize Road  
London NW6 4BT

Middlesex University  
The Burroughs  
London NW4 4BT

### De-briefing Sheet

I would like to take this opportunity to thank you for taking part in this research. If you have any further questions you can contact me at:

Tania D'Aloia  
NSPC, 258 Belsize Road, London NW6 4BT  
[TD240@live.mdx.ac.uk](mailto:TD240@live.mdx.ac.uk)

Or my supervisor:

Dr. Chloe Paidoussis Mitchell  
NSPC, 258 Belsize Road, London NW6 4BT  
[ma@nspc.org.uk](mailto:ma@nspc.org.uk)

Support Groups you may find useful to talk about your interview experience:

Samaritans ([www.samiratans.org.uk](http://www.samiratans.org.uk)), ph: 08457 90 90 90. A 24-hour free confidential telephone support line.

British Association for Counselling and Psychotherapy ([www.bacp.co.uk](http://www.bacp.co.uk)), ph: 01455 883300. A website listing registered counsellors and therapists on a private fee basis.

MIND ([www.mind.org.uk](http://www.mind.org.uk)), ph: 020 8522 1725. A mental health charity providing free and low-cost counselling to people within their local borough.

The British Psychological Society ([www.bps.org.uk](http://www.bps.org.uk)), ph: 0116 254 9568. A website listing national registered psychologists with contact details on a private fee basis.

British Heart Foundation ([www.bhf.org.uk](http://www.bhf.org.uk)), ph: 020 7554 0000. A charity involved in current health advice, research and available community resources.

## Appendix F: Participant Recruitment Poster



### **Research Participants needed for Study into Survivors of Sudden Cardiac**

As part of my final dissertation and doctorate in counselling psychology I am conducting a research study. If you would like to participate in this research and fit the criteria below please contact me, Tania D'Aloia on: [TD240@live.mdx.ac.uk](mailto:TD240@live.mdx.ac.uk) for further information.

**This research aims to explore outlook and emotional well-being of people (aged 30-60) who live years after surviving sudden cardiac arrest.**

The research criteria required for this study:

- To be aged between 30-60 years old and have experienced a sudden cardiac arrest two or more years ago.
- This occurred suddenly while in the home, hospital or outdoor setting.
- This occurred suddenly, without accidental trauma or knowledge of a pre-existing heart condition.
- A crash team had been called to resuscitate.

I am looking to interview individuals on a one to one basis in London for around an hour.

This research project has received full ethical approval from New School of Psychotherapy and Counselling and Middlesex University ethics panel.

*Supervised by:*

Dr. Chloe Paidoussis Mitchell ([ma@nspc.org.uk](mailto:ma@nspc.org.uk))



## **Appendix G: List of Interview Questions**

1. How would you describe what was going on around you at the time of your sudden cardiac arrest?
2. What was it like for you having no recollection of what happened and being told afterwards? If there was a recollection, what was that like?
3. In what way has this experience affected you physically?
4. In what way has this experience affected you on a personal/emotional level?
5. In what way has this experience affected you on a social level i.e. relationships with family, partner, friends, colleagues?
6. In what way has this experience affected you on a spiritual level i.e. values or beliefs around divinity, mortality?
7. Looking back, how have you made sense of this experience?
8. How do you feel about yourself now, in terms of the future and where you see yourself?

## Appendix H: Extract from analysis of one transcript

Notes/Comments	- Recount -	Emergent Themes
Descriptive, linguistic, conceptual	So how would you describe what was going on around you at the time of your sudden cardiac arrest?	Pinching original memory
unwell - chicken pox	1 I was laid on the sofa feeling <u>very ill</u> I had	
Fit - lost consciousness	2 chicken pox at the time...umm...I had what	
Links fit with Cardiac Arrest	3 my wife described as a fit...umm...in terms of	
Defining CA - since distribution left	4 it was a cardiac arrest somehow I came out of	defining cardiac arrest
Fit - SCAR - as a result of	5 that myself...umm...she called an	
Use of very - more emphasis	6 ambulance...umm...much to my protest I said	
Feeling very ill -> losing consciousness/fitting -> regaining consc -> feeling fine	7 I'm fine I don't need one I'm okay but anyway	
maintaining his independence	8 in the ambulance on the way to the hospital I	
"On fire/okay"	9 declined to lie down in the ambulance I said	The Autonomous Self
Resistance - "I'm fine/okay"	10 that I'm fine I'm okay so I sat in the little seat	
Feeling very ill -> feeling fine/okay	11 all of sudden I felt <u>very very</u> light headed and	Denial as protecting self
Denial - "I'm fine/okay"	12 <u>literally</u> that was it that's all I remember	Resistance
Feeling very ill -> feeling fine/okay	13 ...umm...apparently well the ambulance had	Control
Denial - "I'm fine/okay"	14 to stop they had to defibrillate me and bring	
Feeling very ill -> feeling fine/okay	15 me back in, in the ambulance and the next	
Denial - "I'm fine/okay"	16 thing I remember was coming to in	
Feeling very ill -> feeling fine/okay	17 A&E...umm...being told I'd suffered a	
Denial - "I'm fine/okay"	18 cardiac arrest and they had to defibrillate me	
Feeling very ill -> feeling fine/okay	19 and bring me back so...umm...recollections of	
Denial - "I'm fine/okay"	20 the actual event...umm...I was out of it	
Feeling very ill -> feeling fine/okay	21 basically umm I mean a sudden cardiac arrest	
Denial - "I'm fine/okay"	22 is sudden it happens <u>very</u> quickly...umm...	The self as instructive
Feeling very ill -> feeling fine/okay	23 without warning so I think I suffered a minor	
Denial - "I'm fine/okay"	24 <u>one</u> which somehow I came out of myself	
Feeling very ill -> feeling fine/okay	25 initially upon that though my wife had the	
Denial - "I'm fine/okay"	26 good sense and insisted to get me an	
Feeling very ill -> feeling fine/okay	27 ambulance and then in the ambulance I had a	
Denial - "I'm fine/okay"	28 <u>proper one</u> so to speak and they had to bring	
Feeling very ill -> feeling fine/okay	29 me back...umm...when I was in A&E it	
Denial - "I'm fine/okay"	30 happened another three times so I had another	
Feeling very ill -> feeling fine/okay	31 three so I was lying down you know I felt	
Denial - "I'm fine/okay"	32 terrible but remember feeling <u>very cold</u>	
Feeling very ill -> feeling fine/okay	33 actually after and it was a blazing hot day as	
Denial - "I'm fine/okay"	34 well sort of just having a chat and then all of a	
Comments		
1 descriptive		
2 Linguistic		
3 Conceptual		

Swaps 'I' for 'you'  
3rd person - distancing  
himself from exp.

quite a harrowing day - topped  
the enormity of his  
experience.  
uses minimal words next to  
powerful expressive ones and  
words like very next to  
all powerful words.

instincts - intensive care

that was it - factual.  
basic recount.

takes exp to mean still  
self - motor act of it  
was the self  
difficult to stay with?  
initially moves away from exp.  
"get on with it".

important for him to  
get over it, back to  
normal - keeping it  
cognitive.

wasn't very  
nice  
emotional expression -  
perhaps subdued - "not nice"  
uses similar words.  
"feels normal".

what does feeling lucky  
feel like?

uncomfortable to stay with  
feeling  
- uses cognitions to help him  
wants to get back to  
normal quickly.

i.e. lucky, need to go  
home, move on, get back to  
normal.

35 sudden you just feel yourself fade the next  
36 thing you come back again they bring me back  
37 again it kept happening...on the day they  
38 pumped me full of some drug whatever and  
39 stabilized me eventually but...umm...it was  
40 quite a harrowing day and that...umm...  
41 resulted in me being in intensive care for a  
42 week and fully conscious but in isolation.  
43 Intensive care isn't the nicest place to  
44 ...umm...be if your conscious it's designed for  
45 unconscious people again so a week in there, a  
46 week in a high dependency ward...umm...  
47 being monitored and then a week on a general  
48 ward then I came out that was it, basically that  
49 was my sudden cardiac arrest.

#### How did you experience it in the intensive care and then afterwards in the ward?

50 Umm no I mean they stabilized me by that  
51 time so I didn't have any further recurrence of  
52 the cardiac arrest but...umm...at the time I  
53 made the thought that I need to get over this  
54 and get on with it...umm...so the experience  
55 wasn't very nice I was in isolation apart from  
56 intensive care where you have a 1:1 nurse with  
57 you 24 hours a day...umm...but other than  
58 that I was on my own locked in a room in  
59 isolation because I had the chicken pox so  
60 yeah not nice.

#### <sup>rephrase it</sup> No. Do you recall what you felt at the time?

61 Umm...I felt lucky actually I've had a near  
62 miss here I've been really lucky...umm...I just  
63 want to get out, get home and get back to  
64 normal were my thoughts at the time so that's  
65 what I did...came out of hospital and just  
66 carried on as before and just put it down to...I  
67 mean it was associated with the virus going for

Separating from  
self (I, me -> 'you')  
distancing -  
factual sub.

Traumatic

instinctive

Autonomous self.

Re-finding self.  
maintaining sense of  
old self.

Factors on 'Lucky'

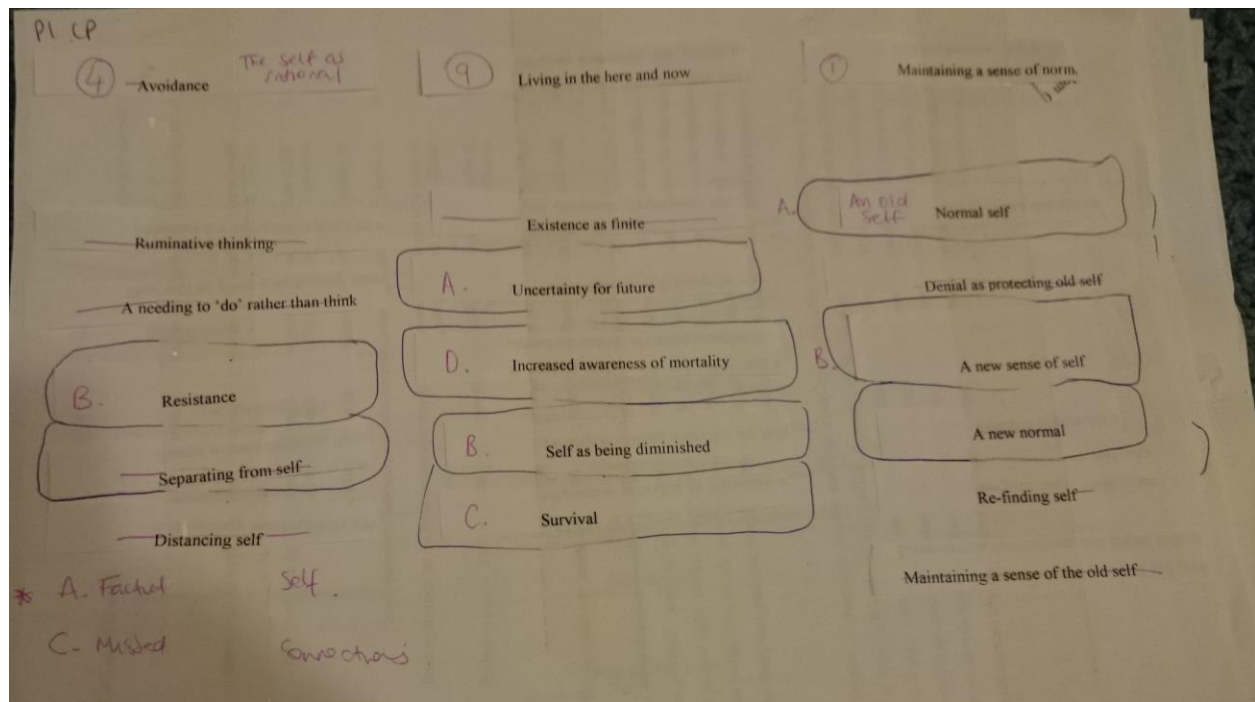
Holding on to 'normal'  
self - normal life.

'normal self'

maintaining sense of  
normality.



## Appendix I: Working on themes of analysis of one transcript



## Appendix J: List of emerging themes from one participant (P6)

### **Memory gap**

An appreciative self

Understanding of SCA

The self as lucky

Uncommon occurrence

### **An angered self**

Piecing together the past

The frustrated self

### **The positive self**

An unsupported self

A reassured self

Incorrect prognoses

A self that is hopeful

### **The self as pragmatic**

A spiritual self

A detached self

A changed self

The self as factual

### **Family cycle of affect**

The rationalised self

Anxiety

The comparative self

Fear

### **The future as uncertain**

The self as protector

A changed reality

The self as protected

Time as limited

A parallel life and death

Getting on with it

### **An autonomous self**

The self as abled

A determined self

## Appendix K: Extract of one table of Superordinate themes

**TABLE OF SUPERORDINATE THEMES AND THEMES IN THE SCA STUDY  
PARTICIPANT SIX**

<b>Themes</b>	<b><i>Page/line</i></b>	<b><i>Extracts</i></b>
<b><i>1. Memory gap</i></b>		
A. Understanding of SCA	3/91-92	“...I didn’t really appreciate what had happened...”
	3/96-98	“...not seeing it happen I didn’t really understand...just thought I’d pull myself back together again”
	3/98-100	“...I just thought it would be something I’d get over but at the time I didn’t realise it was more than that...”
	4/129-131	“...at the time I wouldn’t have known...I’d seen it on TV but I had no understanding really what had gone on...”
	20/885-887	“...that coloured it for us had he never told us that then we would have just carried on as it was so it was a bit of a speed bump in terms of learning...”
	21/921-923	“...made us go away and look and research and say look what is the actual modern crack here is that really the case...”
B. Uncommon occurrence	3/119-121	“...no heart issues prior to that at all so it was just a question to try and figure out what was wrong...”
	8/326-327	“...having 2 shocks in one day which was unprecedented at the time...”
	8/331-333	“...all these things are quite uncommon still, generally, people like me are dead than still breathing...”
	21/917-919	“...I was not the type of patient they were used to seeing and the family thing so yes I think it did make us go after alternative options...”
C. Piecing together a past	2/48-51	“I was asleep and I have no recollection of several days beforehand umm because I think I was in a coma umm actually I’ve no recollection whatsoever of actual events...”

2/51-54	“...I was making funny noises where I was sleeping which woke my wife up and umm she realised something was wrong...”
2/56-58	“...I remember a little bit about a holiday we came back from about a week or so before but that’s all...”
3/86-89	“...I had a strange rewind effect which when my wife asked me questions, my first awareness of where I was I started years back...”
3/100-101	“...my memory after I woke up is fragmented...”
3/108-110	“...everything starts to be more myself as time went on and the stay in hospital is generally a little bit fragmented...”
4/132-134	“...I’ve seen a picture where my son came to visit me and I thought I have no recollection...”
4/140-141	“...seems a bit odd when you say but it’s largely down to what my wife has told me you know...”
4/152-155	“...hilarious she remembers that and I don’t there’s that sort of gap between what I recall and what other people actually saw happen”
4/157-158	“I don’t know I suppose I’m curious about what went on...”

## **2. The positive self**

A. A reassured self	7/292-294	“...the people at the hospital basically said they were amazed by how well I’d coped...”
	10/448-450	“...I’ve also had friends who’ve stayed true sometimes they’ve been around more than others...”
	11/490-492	“...they came over and looked after my little lad before I got back so you know...aware some people are very responsible...”
	12/503-506	“...they were massively supportive which I was surprised by I didn’t know what to expect they’re quite a modern company...”
	15/648-650	“...yes that’s what I would write now so I know I’m similar to what I was then umm so I guess that’s sort of a comfort...”
	21/925-926	“...as it is I should have a relatively normal lifespan ahead of me...”
B. A self that is hopeful	8/333-334	“...I think the volume of knowledge is increasing all the time...”

	12/511-513	"...a lot more confidence going forward, going to work securing work and going to different places..."
	12/513-515	"...working for a local council now and actually, they're fine with it and yes it's fine it's been really really positive..."
	14/607-609	"...I was a positive person before and I'm a positive person now because I know technology is improving all the time ..."
C. A spiritual self	13/585-586	"...I do still believe in...God I mean I'm not a regular church goer but that is still there..."
	14/587-589	"...I'd have to feel that someone is looking out for me otherwise, I wouldn't have pulled through..."
	14/589-591	"...I mean I was as poorly as someone could get and still survive so clearly someone is looking out for me otherwise I wouldn't be here..."
	14/592-594	"...do not think it has particularly changed me as such umm I've always been a spiritual person in the broad sense..."
D. A changed self	12/519-521	"...I'm actually more confident now than I was before the arrest..."
	12/521-524	"...I survived death, therefore, I'm actually quite positive about life now I'm actually more mentally confident in my own space..."
	12/527-529	"...sort of feel if I can get through something like that then anything else is sort of secondary..."
	12/529-531	"...I have a much lower tolerance of whinging [laughs] but you know it's time wasting..."
	12/13/540-544	"...I haven't had sort of a fear of saying 'oh right oh well not sure of your point there' simple as I've been kind of straight forward and matter of fact about it [laughs]..."
<b><u>3. Family cycle of affect</u></b>		
A. Anxiety	8/335-337	"...I was anxious over the period umm and I think I developed mannerisms that drove my wife nuts..."
	8/337-340	"...every time she saw me twitch or wink or make sudden movements she was anxious and her being anxious also made me anxious..."



	8/341-344	"...even now if I make some sudden movement and I don't tell her why I'm doing it then you know her heart starts pounding..."
	8/347-348	"...for her it is posttraumatic what's happened to me..."
	8/349-351	"...she's always been invariably submerged in the impact of what's happened umm and that is difficult..."
	19/835-837	"...I just need to take extra care through any little extra stress particularly as I was 2 days ago I've since seen her awareness go up..."
	19/840-841	"...you know she picks up on all these little things that I don't have a clue about..."
	19/843-846	"...yes, it's difficult and I think sometimes you can forget umm and it is what it is and always there for the mind to remind us of what's happened..."
B. Fear	9/10/402-404	"...it's the little things at the back of your mind she's always very conscious I have heart issues you know
	10/408-410	"...I'll be unconscious so for me, it's actually less stressful in a sense because she's worried how she'll react to it"
	17/762-763	"...it scared the crap out of us...no wanted to fight it..."
C. The self as protector	9/359-361	"...I think in a sense we're more concerned about our partners and families perhaps I didn't really have a choice in the matter it's just the way it is..."
	9/388-390	"...I didn't want to make my wife nervous so I didn't tell her that I thought these feelings were odd..."
	13/573-578	"...it helps my son I think because when his uncle passed away we said to him he's with God now and I think I take comfort knowing he's now old enough that whilst it would be devastating for him I think he could draw comfort from that..."

## Appendix L: Merged Group Themes

<b>Memory gap</b>	An unsupported self	The self as unsupported	The autonomous self
Understanding of SCA	Incorrect prognoses	<b>Fear</b>	Moving on
Uncommon occurrence	<b>The self as pragmatic</b>	Fear of death	Grounded
Piecing together the past	A detached self	Cycle of control	<b>Assurance</b>
<b>The positive self</b>	The self as factual	Avoidance as futile	Diagnosis as assuring the self
A reassured self	The rationalised self	Life as unpredictable (the “what if’s”)	Feeling lucky
A self that is hopeful	The comparative self	Panic attacks	<b>The self as instructive</b>
A spiritual self	<b>The future as uncertain</b>	<b>Emotional self as burdened and overwhelmed</b>	Defining cardiac arrest
A changed self	A changed reality	The stressful self	Defining terms generally for personal understanding
<b>Family cycle of affect</b>	Time as limited	Going through the motions	Making associations
Anxiety	Getting on with it	Disconnection of feelings	Generalizing experience
Fear	<b>The questioning self</b>	<b>Stuck-ness in the ‘now’</b>	<b>The self as rational</b>
The self as protector	Comparison of former self with new self	The minimised self	Factual self
The self as protected	Difficulty accepting self with limitations	Anger at the world	Resistance
A parallel life and death	Changed self	Anger at self	Missed connections
<b>An autonomous self</b>	<b>The self as vulnerable</b>	Resentment	<b>A self that can be controlled</b>
The self as abled	Uncertainties	<b>The informed self</b>	Difficult social situations
A determined self	Losses	No diagnosis/causal explanation	Self-protection
An appreciative self	Self-protection	Fighting to find reason with the unexplainable	Limiting thoughts
The self as lucky	Sharper awareness of own physicality	<b>Maintaining a sense of normality</b>	<b>A self that is uncertain</b>
<b>An angered self</b>			
The frustrated self			

Lack of control over self

Limiting uncertainties

Confusion

**Undesirable feelings**

Traumatic

Fear

Panic

Anxiety

**Living in the here and now**

Uncertainty for the future

Self as being diminished

Survival

Increased awareness of mortality

**The unknown**

A shock

Random occurrence

Reality revisited

Confusion

Uncertainty

Limited knowledge

**Identification with fitness and sport**

Being fit

A confident self

Feeling proud

A sense of achievement

Establishing patterns

A relearned self

Building oneself up

**A controlled self**

The self as managed

Increased awareness of physicality

The protective self

Getting on with it and moving on

**Needing answers**

An angry self

Fear

Anxiety

**An autonomous self**

A reassured self

Balanced sense of life

Finding normality

Outlook as hopeful

**A changed self**

Life changing event

A regained enjoyment of life

Fragility of life (faced death as a possibility)

**Memory gap**

Piecing together what happened

Scattered memory

A disorientated self

A fighting self

**The self as unsupported**

An independent and spirited self

No connection

An isolated self

A changed personality

**Uniqueness of experience**

A new diagnosis

The pacemaker as assurance

Compartmentalising SCA experience

**The self as limited**

Short term memory and word loss

Constant battle regaining memory lapse

Reducing risk and safekeeping self and family

The avoidant self

**Creating the desired life**

Importance of family

Making new experiences

Appreciation of life in the moment

A determined self

The self as supported

Using own experience in supporting others

**A changed self**

A driven life

Time as limited

Self-acceptance

A rational sense of self

**Loss of former self**

Proud

Purposeful

Change as difficult

Comparison of self

**A removed sense of identity**

Confusion

Poor communication

The unknown (memory lapses)

**A vulnerable self**

Isolated

Difficulty in expressing needs

Depression

**Life, death, and suicide**

Relationship with mother

Death (suicide) as an alternative

Multitude of loss

Frustration

**A victimised self**

Assumptive thinking

Passive acceptance

**A sense of needing to endure life**

The rationalising self

The self as powerless

**The self as unacknowledged**

Anger

No validation

Unsupported

**Life as interrupted**

Suddenness of experience

The self as unknown

The confused self

Losses

Heightened sense of physicality

**A different focus/outlook**

A changed self

Reconnection to faith

Finding purpose

Feeling lucky

**Empowerment**

Protecting the self

The autonomous self

The controlled self

**The self as instructive**

The factual self

A sense of moving on

The informed self

**The emotional self**

Recognition of feelings

Fear

Anger

The unsupported self

**Memory gap**

A shock

Confusion

Loss of control and independence

**Uncertainty**

Fear of negative attention

A fighting self

**Compound losses**

SCA represented

An emasculated self

Feeling isolated

**The self as vulnerable**

Anxiety

Suicidal ideation

**An analytical self**

Rationalizing experience

A pragmatic self

Generalizing experience

**An autonomous self**

Values realigned

A supported self

Validation

Outlook as positive

**A changed self**

An un-denying of death

Life as fragile

An appreciative self

Awareness of what is important

**A changed self**

A different outlook

Life as precious

Deeper connection with what is valued

The self as more open and accepting

The positive self

**The emotional self**

Compounded grief

Minimises negative effect of others on self

SCA recollection – NDE

**The supported self**

Reliance on self

The lucky self

Protective family

**The worried self**

Fear

Shock

Panic attacks

Uncertainty

Anxiety

**The vulnerable self**

Initial unwellness – undiagnosed

The insecure self

Life as unpredictable

The unsupported self

Heightened sense of physicality

**A managed self**

The self as reassured

The challenging self

The autonomous self

**SCA represented**

An angry self

A fighting self

Feeling undignified

A detached self

A lucky vs unlucky  
self

**Memory gap**

Fragmented recall

Confusion

Un-realness of  
event

**Death anxiety**

Fearful of negative  
thoughts and  
emotions

A stressful self

An uncontrolled  
self

ICD as  
psychological and  
safety tool

**A pragmatic self**

A practical self

Rationalizing  
experience

The comparable  
self

**Physical  
limitations**

A restricted self

Having endured

Invalidated

A protective self

**Outlook as  
positive**

Sharper awareness  
of own mortality

Time as precious

A confident self

An appreciative  
self

New diagnosis  
hope

The self as  
supported

**64 Superordinate  
themes**

**236 Subordinate  
themes**

**300 total themes**

## Appendix M: Reworking of Group Themes

### 1. THE REALIZATION OF HAVING HAD SCA

#### A shock

Suddenness of experience  
Uniqueness of experience  
Un-reality of event

#### Understanding of SCA

The informed self  
Making associations

#### Memory gap

The confused self  
The unknown  
Piecing together the past  
Detachment

### 2. LOSS OF A FORMER SELF

#### What SCA represents?

A removed sense of identity  
An emasculated self  
Self as being diminished  
Compound losses  
A limited self

#### Comparison of former self with new self

An angry self  
Frustration  
Resentment  
A stressful self

#### Minimal emotional support

The self as unsupported  
Limited professional support  
No validation  
Feeling isolated  
Disconnection

### 3. A CHANGED OUTLOOK

#### A changed self

A self that is hopeful  
A confident self  
A driven life  
A regained enjoyment of life  
The positive self

#### Finding normality

A new normal  
Self-acceptance  
The autonomous self  
Moving on

#### Outlook as hopeful

Outlook as positive  
Time as limited  
Life as precious

#### Sharper awareness of own mortality

Fear of death  
An un-denying of death  
Suicidal ideation

#### Heightened sense of physicality

Focus on body  
The pacemaker as assurance  
ICD as psychological and safety tool

#### Deeper connection with what is valued

Awareness of what is important  
Importance of family  
Reconnection to faith  
Using own experience in supporting others

#### An appreciative self

Life as fragile  
Life as precious  
A lucky vs unlucky self

### 4. LIVING IN THE HERE AND NOW

#### Uncertainty for the future

Self-protection  
Seeking causal assurances  
Life as unpredictable

#### A vulnerable self

The self as vulnerable  
Anxiety  
The worried self  
Undesirable feelings

## Appendix N: Group Themes

### 1. IMMEDIATE IMPACT: AWAKENING TO SCA

#### 1A. Un-realness of event

A shock

Detachment

#### 1B. Memory gap

The confused self

Piecing together the past

#### 1C. Understanding of SCA

The informed self - seeking causal assurances

### 2. THE EXPERIENCE OF RECOVERY: WHAT SCA REPRESENTS

#### 2A. Comparison of former with new self

Frustration

An angry self

#### 2B. Self as being diminished

Resentment

Compound losses

#### 2C. Sharper awareness of own mortality

Fear of death

An un-denying of death

Suicide as a possibility

#### 2D. Heightened sense of physicality

Focus on body

Awareness of ICD or Pacemaker: assurance versus fear

A limited self: self-protection

#### 2E. Minimal emotional support

The self as unsupported

Limited professional support

### 3. THE POST RECOVERY EXPERIENCE: LIVING IN THE HERE AND NOW

#### 3A. Making sense of SCA experience

A lucky versus unlucky self

#### 3B. A changed outlook: increased confidence, hope, and positive aspect

A confident self

A hopeful and positive self

**3C. A changed outlook: deeper connection with what is valued**

A regained appreciation for life

Importance of family

Reconnection to spirituality

Finding meaning in supporting other survivors



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